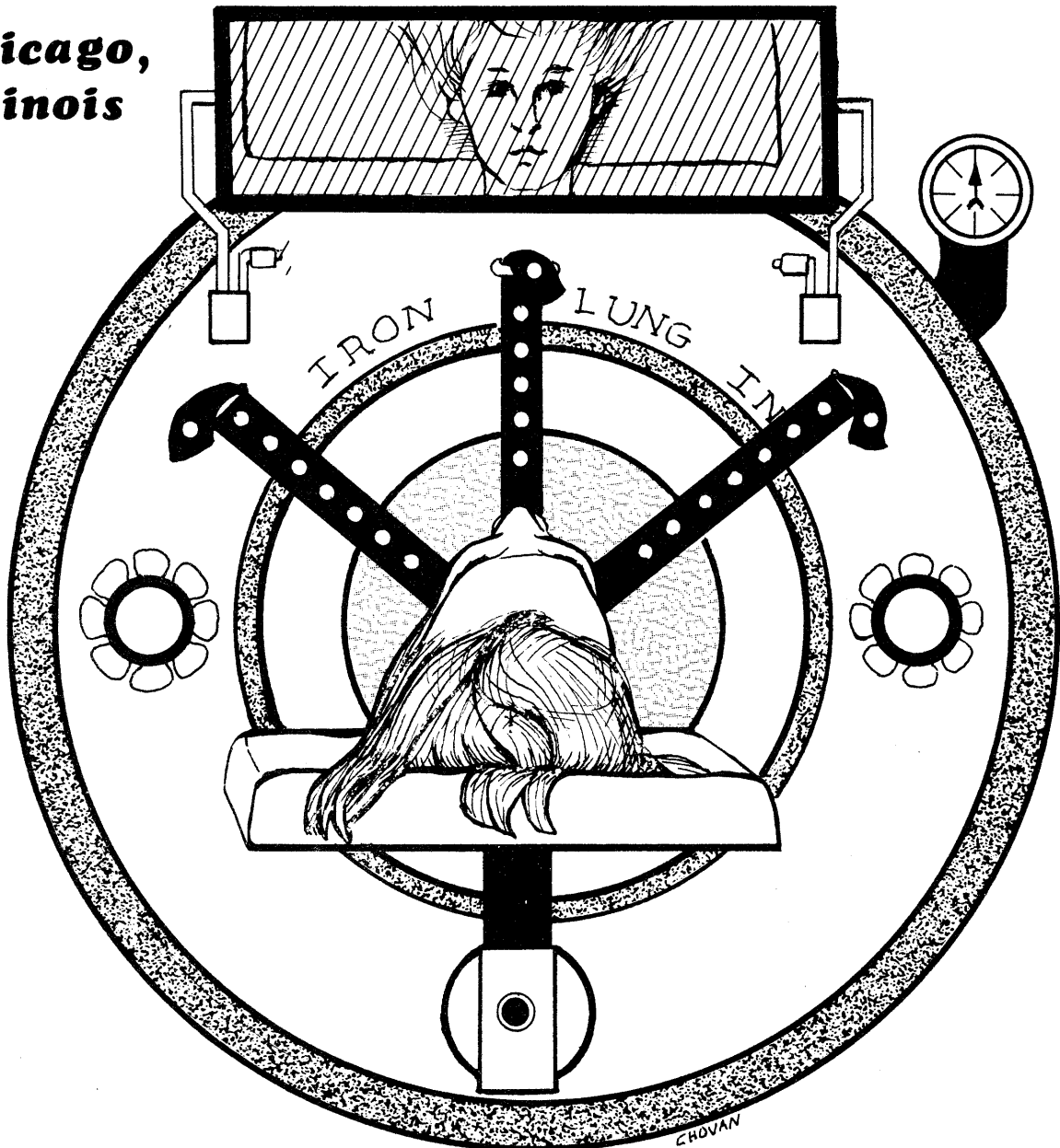


proceedings of an international symposium

What Ever Happened to the Polio Patient ?

Chicago,
Illinois



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CONTENTS

| | <u>Page</u> |
|--|-------------|
| PROGRAM | 1 |
| GLOSSARY OF PHOTOGRAPHS | 11 |
| SUMMARY OF SYMPOSIUM | 23 |
| PROCEEDINGS | |
| <u>Session I</u> The Past: The Experience of the Polio Epidemic | 33 |
| <u>Session II</u> The Present: A Crisis? The Need to Develop Cost- Effective and Personal Services for Polio Survivors | 71 |
| <u>Session III</u> The Present: Technological Issues - Are Past Techniques and Practices Developed During the Polio Crisis Applicable to Meet Present Needs? | 97 |
| <u>Session IV</u> The Present: The Regional Approach to Meeting Needs of Polio Survivors Outside of the Medical Center | 125 |
| <u>Session V</u> Premature Aging Problems of Polio Survivors | 155 |
| <u>Session VI</u> The Future: Can Modern Organizational Approaches Today Meet the Challenge of Complex Problems of Tomorrow? | 199 |
| PARTICIPANTS | 237 |
| APPENDIX | |
| <u>Appendix A</u> Program Documents (distributed to participants) | 249 |
| <u>Appendix B</u> Process Documents (symposium objectives, advance letters, forms and fact sheets, hotel layout) | 267 |
| <u>Appendix C</u> Suggestions for the Media Symposium Evaluation Release (mailed to participants) | 297 |

PROGRAM

SESSION I

THE PAST: THE EXPERIENCES OF THE POLIO PATIENT

Opening Remarks

- Henry B. Betts, M.D. 35
 Chairman, Department of Rehabilitation Medicine,
 Northwestern University Medical School
 Vice-President and Medical Director,
 Rehabilitation Institute of Chicago
 Chicago, Illinois
- Gini Laurie 37
 Co-editor and Publisher
Rehabilitation Gazette
 St. Louis, Missouri

Definition and Scope of the Crisis

- Allen I. Goldberg, M.D., Moderator 43
 Medical Director, Division of Respiratory Care,
 Department of Anesthesia, Children's Memorial Hospital
 Assistant Professor of Anesthesia and Pediatrics,
 Northwestern University Medical School
 Chicago, Illinois

Health-Care Delivery Perspective

- David Dickinson, M.D. 45
 Chief, Clinical Affairs
 University of Michigan Hospital
 Ann Arbor, Michigan

Reactor

- Augusta Alba, M.D. 49
 Director, Howard A. Rusk Respiratory Rehabilitation Center
 Associate Director, Goldwater Memorial Hospital
 Associate Professor of Neurology and Rehabilitation Medicine
 New York University School of Medicine
 New York, New York

Consumer Perspective

- Ronald Doneff, M.D. 53
 Hobart, Indiana

Reactor

- Jack Genskow, Ph.D. 57
 Professor of Rehabilitation, Sangamon State University
 Springfield, Illinois

Organizational Perspective

- André Dessertine 59
President, Association d'Entraide des Polios Handicapés (ADEP)
Paris, France

Reactor

- Audrey J. King, M.A. 63
Ontario Crippled Children's Centre
Toronto, Ontario, Canada

**What Factors Led to a Successful Approach
to Meeting the Needs of Polio Patients?**

Audience Participation with panel of invited guests, including:

- Adolph D. Ratzka 67
Stockholm, Sweden
Rev. Patrick Lewis, C.S.S.P. 67
San Francisco, California

SESSION II

**THE PRESENT: A CRISIS? THE NEED TO DEVELOP
COST-EFFECTIVE AND PERSONAL SERVICES FOR POLIO SURVIVORS**

- Ernest W. Johnson, M.D., Moderator 73
Professor and Chairman, Department of Physical Medicine
Ohio State University Hospitals
Columbus, Ohio

Health-Care Perspective

- Alice Nolan, R.N., M.A. 75
Research Associate
Goldwater Memorial Hospital
New York, New York

Reactor

- Ann A. Bailey, M.D. 79
Staff Physician
Roosevelt-Warm Springs Institute for Rehabilitation
Warm Springs, Georgia

| | <u>Page</u> |
|--|-------------|
| Consumer Perspective | |
| Margaret C. Pfrommer Consumer Advocate and Research Associate Northwestern University Rehabilitation Engineering Program, Department of Orthopaedic Surgery Northwestern University Medical School President Illinois Congress of Organizations of the Physically Handicapped Chicago, Illinois | 81 |
| Reactor | |
| August W. Christmann Executive Director Illinois Congress of Organizations of the Physically Handicapped Chicago, Illinois | 85 |
| Organization Perspective | |
| James C. Campbell, President LIFECARE Services, Inc. Boulder, Colorado | 87 |
| Reactor | |
| André Dessertine President, Association d'Entraide des Polios Handicapés (ADEP) Paris, France | 91 |
| What Factors Today Must be Considered to Meet Complex Health-Care Needs? | |
| Audience participation with panel of invited guests, including: | |
| Joseph M. Kaufert, M.D., Ph.D. University of Manitoba Manitoba, Winnipeg, Canada | 93 |
| Russell L. Beeson LIFECARE Services, Inc. Pacheco, California | 94 |

SESSION III

THE PRESENT: TECHNOLOGICAL ISSUES - ARE PAST TECHNIQUES AND PRACTICES DEVELOPED DURING THE POLIO CRISIS APPLICABLE TO MEET PRESENT NEEDS?

The Evaluation of Technology in Response to Polio

| | |
|--|----|
| John O'Connor, Moderator Vice-President and General Counsel National Foundation - March of Dimes White Plains, New York | 99 |
|--|----|

Film

Ernest W. Johnson, M.D.
Professor and Chairman, Department of Physical Medicine
Ohio State University Hospitals
Columbus, Ohio

Health-Care Perspective

Augusta Alba, M.D. 101
Director, Howard A. Rusk Respiratory Rehabilitation Center
Associate Director, Goldwater Memorial Hospital
Associate Professor of Neurology and Rehabilitation Medicine
New York University School of Medicine
New York, New York

Reactor

Ernest W. Johnson, M.D. 107
Professor and Chairman, Department of Physical Medicine
Ohio State University Hospitals
Columbus, Ohio

Consumer Perspective

Theodor A. Dukes 109
Research Scientist
Princeton University
Princeton, New Jersey

Reactor

Herbert S. Merrill 113
Engineer, State of Maine Rehabilitation Council
Falmouth, Maine

Organizational Perspective

Carlton Bishop 115
LIFECARE Services, Inc.
Augusta, Georgia

Reactor

Robert B. McCown, Ph.D. 117
Staff Scientist and Engineer
Intermagnetics General Corporation
Albany, New York

**How Can We Apply "Space-Age Technology" to Meet
Health-Care Needs in a Climate of "Limited" Resources?**

Audience participation with panel of invited guests, including:

Eugene Murphy, Ph.D. 121
Veterans Administration
New York, New York

SESSION IV

**THE PRESENT: THE REGIONAL APPROACH TO MEETING NEEDS OF
POLIO SURVIVORS OUTSIDE OF THE MEDICAL CENTER**

**What are the Institutional Alternatives
that are Available on a Regional Basis?**

Thomas R. Schworles, Moderator 127
Chairman, Education Committee
Illinois Congress of Organizations of the Physically Handicapped
Chicago, Illinois

Health-Care Perspective

Geoffrey T. Spencer, M.B., F.F.A.R.C.S. 129
Phipps Respiratory Unit, South Western Hospital
Consultant, St. Thomas's Hospital
London, England

Reactor

Augusta Alba, M.D. 137
Director, Howard A. Rusk Respiratory Rehabilitation Center
Associate Director, Goldwater Memorial Hospital
Associate Professor of Neurology and Rehabilitation Medicine
New York University School of Medicine
New York, New York

Consumer Perspective

Judy Heumann 141
Center for Independent Living, Inc.
Berkeley, California

Reactor

Valerie Brew Parrish 147
Associate Director, Career Planning and Placement Center
Southern Illinois University
Carbondale, Illinois

Organizational Perspective

André Dessertine 151
President, Association d'Entraide des Polios Handicapés (ADEP)
Paris, France

SESSION V

PREMATURE AGING PROBLEMS OF POLIO SURVIVORS

| | |
|---|-----|
| Allen I. Goldberg, M.D., Moderator | 157 |
| Medical Director, Division of Respiratory Care, Department of Anesthesia, Children's Memorial Hospital Assistant Professor of Anesthesia and Pediatrics, Northwestern University Medical School Chicago, Illinois | |
| Define the Issue | |
| Frederick M. Maynard, M.D. | 159 |
| Assistant Professor, Physical Medicine and Rehabilitation University of Michigan Ann Arbor, Michigan | |
| Analyze the Issue | |
| Ann A. Bailey, M.D. | 169 |
| Staff Physician Roosevelt-Warm Springs Institute for Rehabilitation Warm Springs, Georgia | |
| Solve the Issue | |
| Augusta Alba, M.D. | 173 |
| Director, Howard A. Rusk Respiratory Rehabilitation Center Associate Director, Goldwater Memorial Hospital Associate Professor of Neurology and Rehabilitation Medicine New York University School of Medicine New York, New York | |
| Harriet Bell | 177 |
| President, Polio Survivors Association Goldwater Memorial Hospital New York, New York | |
| Mary Jay Bullock, O.T.R. | 179 |
| Rehabilitation Medical Department Johns Hopkins Hospital Baltimore, Maryland | |
| D. Armin Fischer, M.D. | 181 |
| Chief, Chest Medicine Service Rancho Los Amigos Hospital Downey, California | |

| | <u>Page</u> |
|---|-------------|
| Panel Discussion - Introductory Remarks | |
| Allen I. Goldberg, Moderator | 185 |
| Medical Director, Division of Respiratory Care, Department of Anesthesia, Children's Memorial Hospital Assistant Professor of Anesthesia and Pediatrics, Northwestern University Medical School Chicago, Illinois | |

The Issues that Concern the Polio Survivor

| | |
|---|-----|
| Panel Discussion (Summary of Special Meeting - October 15) | |
| Judy Heumann | 195 |
| Director, Center for Independent Living Berkeley, California | |
| Marilyn Saviola | 196 |
| Rehabilitation Counselor Goldwater Memorial Hospital New York, New York | |

SESSION VI

**THE FUTURE: CAN MODERN ORGANIZATIONAL APPROACHES TODAY
MEET THE CHALLENGE OF COMPLEX PROBLEMS OF TOMORROW?**

What is the Future for the Polio Survivors?

| | |
|---|-----|
| Henry B. Betts, M.D., Moderator | 201 |
| Vice-President and Medical Director Rehabilitation Institute of Chicago Chicago, Illinois | |

Health-Care Perspective

| | |
|---|-----|
| Geoffrey T. Spencer, M.B., F.F.A.R.C.S. | 203 |
| Phipps Respiratory Unit, South Western Hospital Consultant, St. Thomas's Hospital London, England | |

Consumer Perspective

| | |
|--|-----|
| Linda Bienick | 209 |
| Communications Specialist Continental Illinois National Bank Member, Access Living Board of Directors Chicago, Illinois | |

Organization Perspective

| | |
|---|-----|
| André Dessertine | 217 |
| President, Association d'Entraide des Polios Handicapés (ADEP) Paris, France | |

Audience participation via directed comments to moderator
and invited participants by selected panel:

Health-Care Provider

Mathew Lee, M.D. 219
Director, Department of Rehabilitation
Goldwater Memorial Hospital
New York, New York

Consumer Perspective

Judy Heumann 221
Director, Center for Independent Living
Berkeley, California

Keynote Address

C. Everett Koop, M.D. 225
Deputy Assistant Secretary for Health
Department of Health and Human Services
Surgeon General Designee of the United States
Washington, D.C.

Final General Discussion

Henry B. Betts, M.D., Moderator 233
Vice-President and Medical Director
Rehabilitation Institute of Chicago
Chicago, Illinois

SUMMARY OF SYMPOSIUM

SUMMARY OF SYMPOSIUM

Prior to the successful immunization against polio, devastating epidemics, peaking in the early 1950s, disabled millions of young children and active adults. All over the world, regional multidisciplinary efforts called into operation existing technological and organizational resources and began developing new approaches to meet the challenges.

In human and economic terms polio created a crisis atmosphere. People -- often in the prime of life -- suddenly were struck. Numerous polio patients were isolated in medical institutions that were ill-equipped to give proper care. Large sums of money were given to a pioneering voluntary agency, the National Foundation - March of Dimes. Leaders came forth to integrate the disciplines of the scientific community and established quality respiratory care centers. The survivors, through a combination of medical care, education, activism, and courage, have achieved varying degrees of success in independent living and in social and vocational mainstreaming.

Since the 1950s, we have built upon the foundations initially developed in response to widespread polio. The multidisciplinary approach and technological advances of that era have evolved into modern rehabilitation and critical care medicine. As a result, many lives have been saved and the life span increased for countless more. Recent and older polio survivors represent the successful efforts of many people working together with diverse interests and backgrounds.

The success of this effort has also created a crisis in our time in health-care delivery. Current approaches do not meet the needs of modern survivors in that they do not provide the social and economic options for a reasonable quality of life. Many children and adults now depend upon technological support devices to survive.

These "disabled" people require, or will be requiring, the technology that will assist them in overcoming a barrier that presently limits their ability to learn, work, and live. A new generation of people has been created, that requires a diversity of alternatives in order to live full, productive lives. We have succeeded, but we have not dealt with the question, "What next?"

By not meeting the needs of the survivors of our current health-care system, unreasonable demands are made upon existing acute care and rehabilitation services. We are in danger of reducing the existing quality and availability of health care if we use our resources inappropriately and inflate the costs. Because of attitudes which limit our thinking and working, other resources that are available are not being applied to meet these needs.

"What ever happened to the polio patient?" Those survivors -- the former generation that pioneered the advances -- seem to be "prematurely aging," and no one really understands why.

All survivors of modern health care require a consolidation of effort -- a broad-based multidisciplinary approach involving all interested and involved sectors -- to understand the problems and develop workable solutions. The goal of this symposium was to demonstrate a process that can be used as a model to approach modern complex health-care issues. Our objectives directed our working together to understand the current unmet needs of the technology-dependent polio survivor so that we might develop a workable approach for providing the reasonable services these people need.

Our modern crisis has not yet achieved the notoriety or impact of the polio epidemics. Polio attacked beautiful,

healthy children and adults in the midst of productive careers. A large portion of the world's population was affected, and Americans particularly were made aware of the polio threat by a United States President being afflicted. The international reaction generated concern and fear. In contrast, today's crisis has not yet reached public attention. People do not know that there is an urgent need to provide state-of-the-art health care and services. They assume that health care is a right and is always available. It is not.

All the disabled people today who require health care and support services are facing a crisis. There is an urgent need for centers to provide appropriate care, to educate consumers and medical service personnel, and to disseminate information to the public, the consumer, and the medical community. Candidates for independent living or attendant home care need increased support from health-care agencies. However, these agencies do not have anywhere near the funds that were given by generous people to the March of Dimes.

The polio survivor and other technology-dependent people today have medical, economic, social, and -- possibly -- psychological problems. Medically, problems arise because of the lack of appropriate education and training programs for doctors, nurses, and technicians to meet the needs of respiratory-disabled and mobility-limited people. Economically, both categories of survivors experience problems with insurance, third-party payment, and income maintenance. Socially, they both experience expected problems with accessibility, housing, transportation, and attendant care. Psychologically, problems may arise from a diversity of social pressures and real or imagined threats to independent living, because of what are believed to be socially imposed patterns in life style and in setting vocational and educational priorities.

Today's medical community is increasingly unfamiliar with polio, and

there is a growing lack of the kinds of equipment and services needed in its treatment. The survivors suffer from additional problems related to inactivity, such as brittle bones, phlebitis, deep-vein thrombosis, and pulmonary insufficiency. Lack of exercise, being overweight, and high alcohol or drug consumption are common enough in the general public; in the polio survivor these excesses and omissions are magnified, with disastrous effects.

Polio survivors experience another problem: premature aging, which causes fear and loss of function. A complex phenomenon, premature aging has not yet been adequately investigated by the medical community. Some of the many questions it poses are:

- . What is the relationship of polio to amyotrophic lateral sclerosis?
- . Is the loss of functions primarily caused by nerve cell or muscle cell loss?
- . Are the survivors' muscles at increased risk for weakness with overexertion; does "post-polio amyotrophy" get worse with overuse?
- . What is that undiagnosed pain all about?

All of these are vital issues to polio survivors.

All disabled individuals have critical educational requirements. They must know their capabilities. They must know how to be assertive and communicative with doctors, nurses, and therapists, how to accept changes in their bodies, and how to combat depression. An advantage the polio survivor has over the newly disabled person is the knowledge he has gained about his own body's functions and requirements. The polio survivor who has had experience and has solved most of these problems can provide information to help the medical community ease the crisis faced by technology-dependent

people. As polio survivors age, we in turn must provide them with the care and support for their unending contributions. Polio survivors have become important role models and have demonstrated what "the disabled" can accomplish. Polio survivors have changed the public's perception of "the handicapped" and have become contributing and independent members of society.

Care and support for the respiratory-disabled, technology-dependent person can best be provided in regional centers. Past experience with polio has shown us the value of the regional approach. The March of Dimes introduced the concept by establishing regional polio centers in the 1950s. In these centers, multidisciplinary teams met the needs of technology-dependent people. During epidemic periods the centers provided professional staffs, equipment, and programs. Expertise and resources continually rose to meet the critical need. These centers initiated home care programs which were safe, appropriate, and dramatically cost-reducing. Duration of hospital care was decreased by these well-planned programs from an average of one year to seven months. Home care costs were 10% to 25% of hospital costs.

Certainly as important as the cost-effectiveness were the human benefits that resulted. Without the outreach efforts of the regional centers, 40% of those who were at home would have had to remain in custodial care for the rest of their lives. Out of these outreach efforts in Europe has come the modern development of large-scale home ventilation programs and independent living centers for the respiratory-disabled person.

It was in the 1950s that the prototypes of modern respiratory support devices were adapted to keep the polio patient alive. Mechanical aids for breathing -- still in use by polio survivors -- include the rocking bed, the iron lung, the cuirass, and the small portable ventilator for mouth positive pressure ventilation. Although the modern medical staff

understands and uses far more expensive and complex ventilator-assist devices, many of today's hospital staffs do not know how to use the simpler, but effective, equipment of the past. Although there is a continuing development of new technology in the medical, computer, and space industries, the technology-dependent individual has not fully benefited by the potential and economically feasible application of these scientific advances. This is due in part to inadequate dissemination of information, a lag in the production and marketing of technical aids, and a reluctance on the part of professionals to accept the application of these aids as an integral part of the rehabilitation process.

The respiratory-disabled person, or any survivor who is technology-dependent, deserves a sense of medical security and an opportunity to lead a high-quality life which should include social integration. Individuals have the responsibility and the right to determine what care is required for their well-being. Because of the general absence of public awareness and the failure on the part of the medical community to implement existing knowledge, the polio survivor needs to explore and promote alternative care systems.

Disabled individuals have the responsibility and right to choose their own appropriate living arrangements with whatever accessibility and transportation they require. Locally, community agencies must support these aims by offering services such as attendant care referrals, housing placements, individual counseling, and family education. Regionally, a service organization must be created to provide needed case management monitoring, consultation and technical support. A registry, to document and disseminate information and education for professionals, consumers, health-care service providers, and other interested and involved groups, must be set up. Nationally, policy leaders in the public and private sector must coordinate efforts to guarantee appropriate health care and related services for all people with disabilities. By the

leaders' working together, this can be done at dramatically reduced cost!

To achieve these goals, we must understand and apply a decision-making process. We must gather the information, identify the problems, assess the needs, determine the priorities, formulate the objectives, explore the alternatives, analyze advantages and disadvantages, and select appropriate actions. We must approach already established resources, namely, those foundations and funds which have money designated for rehabilitation and care for the disabled. There are large sums of monies that are not used for this purpose because the trustees are not aware of the large number of respiratory-disabled and potentially respiratory-disabled people. We have to increase public awareness through the media and identify and directly address the officials in charge of those trusts. Then we must act in an organized way, flexibly and realistically, and evaluate our results. In this way, modern organizational approaches presently in operation can meet the challenge of the complex problems of today -- and tomorrow.

The concluding session of this symposium provided remarks from world-respected leaders whose individual and organizational accomplishments were particularly relevant to the issues raised by the symposium. These included health-care providers:

Geoffrey T. Spencer, M.B., F.F.A.R.C.S., London -- Pioneer of respiratory rehabilitation and home ventilation in Britain;

Henry B. Betts, M.D., Chicago -- National leader of rehabilitation medicine and accident prevention; medical director of an international model for patient care, research, education, and training;

Mathew Lee, M.D., New York -- Director of broad-based, total approach to institutional and community-based respiratory rehabilitation services;

C. Everett Koop, M.D., Washington -- Pediatric surgeon, innovator of corrective procedures for disabling birth

defects, and Surgeon General Designee of the United States (1981);

... consumer advocacy leaders:

Judy Heumann, Berkeley -- Director of internationally famous independent living program (west);

Linda Bienick, Chicago -- Board member of Access Living, national model independent living program (midwest);

... and organizational pioneer:

André Dessertine, Paris -- President, ADEP, documentation center, regional home ventilation program, and independent living center for technology-dependent survivors.

To summarize these eloquent statements would not do justice to either their creative thinking or vital messages. The editorial board refers to them directly. Taken together, they prove that no complex problem in modern times is beyond our potential to successfully address it, if we work together to find solutions.

Some Remarks about the Process

The content of the proceedings has been edited to facilitate comprehension of the issues raised and to focus on the recommendations that came out of our meetings. We hope that this emphasis on clarity will make the document more useful to the reader. To show the validity of the conclusions arrived at, some description of the process of this meeting is also in order.

From the outset, the planning, public relations, the hotel and transportation arrangements, the development of volunteer services, the coordination of the hosts and assignment of responsibilities, the evaluation of the meeting, and the editing of the proceedings -- everything was a joint venture of the many concerned people and interest groups involved.

The symposium consisted of six half-day sessions. The first four sessions were smaller (150 people) working groups; the

last day's two sessions were larger (200 to 250 people) and more formal. Session I dealt with a review of the past experiences during the polio epidemics. Sessions II, III, and IV dealt with the present: the definition and description of a health crisis, the analysis of both technological and organizational practices, and the needs of today.

The symposium objectives and the specific session objectives were defined and distributed in advance to all meeting participants. As a result, all participants came prepared to go to work. For a better analysis of the objective, each session's objective was further divided into three perspectives: health-care provider, consumer, and service organization (e.g., equipment vendor, care taker services, insurance, government, voluntary associations). For each perspective, two invited guests, a presenter and a reactor, came to the meeting prepared to meet the objective with a discussion that would stimulate the group's working together for the remainder of the session.

After intermission, each session offered the opportunity for maximal group involvement. Spontaneous groups of 15 to 20 people formed around a flip-chart. Team facilitators (moderators, presenters, reactors, panelists, and volunteers) led discussions that focused upon given questions (see "Program, Session Objec-

tives"). The discussions were recorded on the flip-charts by a group-appointed recorder. These discussions ran smoothly because of the high degree of motivation among the participants and the direction given by professional group facilitators who volunteered to be at this meeting. The proceedings contain the summary of these group discussions.

It is noteworthy that Session IV was so intense, the energy of discussion so great, and the anticipation of the last day so marked, that it was continued after a dinner break into the late evening. The summary of that discussion is provided in the text of the group discussions of Session V.

Session V, which dealt with the present status of post-polio aging and survival issues, followed a more traditional format. After the prepared discussions, the audience participated by means of written questions which were then answered by a selected group of panelists. This format seemed the best way to provide an opportunity to raise the multiple concerns of today's polio survivor.

Session VI, which was addressed to planning an approach to the future, permitted the participants to hear formal presentations by respected leaders as they attempted to deal with the crisis which was so well defined by this working symposium.

SESSION I

THE PAST: THE EXPERIENCE OF THE POLIO EPIDEMIC

OPENING REMARKS

Henry B. Betts, M.D.

Vice-President and Medical Director,
Rehabilitation Institute of Chicago, Chicago, Illinois

Professor and Chairman, Department of Rehabilitation Medicine,
Northwestern University Medical School, Chicago, Illinois

This conference marks a noteworthy event because it focuses upon a vital issue -- that of the unmet needs of polio-disabled persons. It will celebrate the International Year of Disabled Persons in a way that will accomplish something by finding solutions.

The polio epidemics, and the solutions they generated, had an enormous effect not only on the movement for disabled persons but also on the development of rehabilitation medicine. The polio survivor became the pioneer of new approaches and of change in the public attitude toward the disabled community. We owe a great debt to the polio survivor. This conference is a beginning in the attempt to repay that obligation.

* * * * *

This Conference: A Significant Approach to Unmet Needs

This conference is probably the most intricate activity that the Institute has brought about in years. We train about 4,500 people a year, and we have had dozens and dozens of conferences, but nothing could be more important and more significant than this conference. It represents an approach to a truly vital issue, that of unmet needs, an issue that has been ignored for a long time.

The conference also represents an extremely significant approach to accomplishing something in this International

Year of Disabled Persons. It gives us all an opportunity to see where there are problems, approach them constructively, and find some solutions.

Significance of the Polio Crisis and the Solutions It Generated

In a number of ways, polio has been one of the great national dramas in this country. The epidemics, of course, were devastatingly dramatic, more dramatic than any of us would ever like to see again, and they moved the nation in a variety of ways. They certainly affected all Americans emotionally and many physically. There was a great national outpouring of concern.

The next drama, fortunately, was that of finding something to do about polio. The effectiveness of the vaccines was stunning and remarkable -- something all of us remember and treasure. But even before there were vaccines, there were very significant happenings in the way polio was approached. The implications of some of these approaches proved to be very far-reaching.

In this country and throughout the world, the whole approach to the disabled is generally based on that taken to polio patients in the 1950s. Until the polio crisis, the disabled were not taken much into consideration by anyone. But in the aftermath of the polio epidemics there was a great outpouring of concern for

polio survivors. These individuals, frequently children, struggled heroically to overcome their disabilities. And, because the President too had polio, a great deal of consideration began to be given it.

The development of rehabilitation medicine, including the team approach, and the development of public concern for disabled people grew out of the national concern for those who were polio survivors. Looking back, we can see that a great deal has been built upon those initial steps to meet the challenge that polio presented.

Significance of the Polio Survivor

Those who survived, those who made it through, have been the heroes in the movement of the disabled. You have had a major effect on the lives of disabled people throughout the world. You and others like you showed the way, showed that the disabled could be integrated in the mainstream of life and be significant contributors to society. Until you and those like you came along, very little consideration was given to such ideas. Disabled people were tucked away in basements and attics, and the existence of disability was shrouded in embarrassment and silence. Certainly people were not, as we say now, "mainstream."

Purpose of the Conference

Because you were among the first to show what could and should be done, we feel a very strong obligation to you. We in this room, the medical community at large, and the nation as a whole, feel a debt of gratitude toward you -- not pity, but I hope some compassion, and I hope some caring about the problems you face now. We feel grateful for the way in which you led so many other people out of despair. You made it possible to develop

the approach to the disabled and to rehabilitation that we have in this country today. It is you who have brought about the general national concern that now exists for the disabled. We hope that this conference, by finding ways in which you can go on and meet your needs more satisfactorily, will be the beginning of repaying you for your kindnesses in the past.

A Perspective and a Commitment

This conference, too, is a somewhat pioneering endeavor. We have brought together people who are committed to a careful analysis of the issues, and who will generate proposals that will lead to action.

Background of the Meeting

The activators behind this conference, those who first conceived it and made it happen, are Allen Goldberg and Gini and Joe Laurie. It was Allen Goldberg who first brought to my attention the issues of this conference. He is an extremely dynamic and very moving aspirant for finding solutions to the unmet needs we shall be discussing here. After Gini and Joe Laurie suggested to him the ideas for this meeting, he pushed for it. He got it, and you deserve it. You deserve him because he has made a strenuous effort to bring this conference about.

The conference itself is the realization of the dream of Gini and Joe Laurie. They have had an enormous impact in everything that relates to disabled people, but especially to polio. Co-editors of the Rehabilitation Gazette in St. Louis, they have been pioneers for your causes. They are fantastic in their inspiration, knowledge, and the way they have pursued an attempt to meet the goals they have recognized for so many years.

INTRODUCTORY REMARKS

Gini Laurie

Co-editor and Publisher,
Rehabilitation Gazette, St. Louis, Missouri

Prior to the polio vaccine, the regional center concept of polio and respiratory care, funded by the National Foundation - March of Dimes, concentrated on expensive care by coordinated teams. Huge savings in health care costs, effective expansion of needed services, and improvement in people's lives resulted. The economic and human benefits are presented with important documentation for review.

The contrasting post-vaccine era required the organization of those concerned for the survival of the disabled population. One successful campaign to arrange attendant care services demonstrated a formula, a process, worth restating and reinvigorating at this conference. It is by combining our multiple skills and involving all interests that future efforts can succeed in benefiting disabled people who have unmet needs for services.

* * * * *

Welcome to you all again from Joe and me and thanks to all of the creators of this conference: the Planning Committee, the Rehabilitation Institute of Chicago, the sponsoring organizations, the volunteers, our friends, everyone who has helped, but, especially, all of you who come from far and near to be here.

The Regional Center Concepts of Polio Respiratory Care

During the 1950s, a superb system of regional respiratory centers was created

and funded by the National Foundation for Infantile Paralysis, as it was known then, now the National Foundation - March of Dimes. The life span of most of those centers was less than a decade, but the impact on physical medicine, independent living, and rehabilitation was tremendous.

The first two centers were set up in Boston and Houston in 1950 because the March of Dimes had done a study (Laudauer, 1958) which showed that it was spending vast sums on a handful of respiratory-dependent people scattered around the country. The study recommended the setting up of regional centers with multidisciplinary teams. This was done, and eventually there were 16 centers at teaching hospitals and medical schools around the country. The timing was perfect because, when the ghastly epidemics of 1953 and 1955 came along, the centers were ready and waiting.

During those terror-ridden epidemic years, the money poured into the March of Dimes. It paid for everything at the centers: the professional staff, inpatients and outpatients, care of the equipment and its maintenance, home care, home modifications, and the salaries of attendants. The centers generally had a superb team spirit that included the staff, the patients, and the families. Continuing home care was an integral part of the whole system. Before patients went home they were prepared to instruct others in the use of their respirators and to hire and train attendants.

Enormous Cost-Effective Benefits of Regional Centers

The centers and home care resulted in tremendous financial savings and a greater degree of independence and self-sufficiency than was ever dreamed possible for people so severely disabled. Here are a few of the cost-effective figures. The average hospital time was cut from more than a year to seven months. The home care costs were one-tenth to one-fourth of hospital costs.

As of January 1959, the count showed that in the United States the total number of respiratory-dependent people was 1,756; those at home numbered 1,271. Without those centers, 40% of those who were at home would have had to remain in custodial care the rest of their lives.

The Post-Vaccine Era - A Search for Services

So successful was the March of Dimes' vaccine research that the flow of dimes slowed and the largesse of the March of Dimes had to be curtailed. Eventually, the centers had to be closed. However, the National Foundation's responsibility for equipment and its maintenance continues to this day.

When, as of July 1959, the March of Dimes had to stop home care funding, the great scrounge for attendant monies began. It still continues, and it still creates a need to band together to try to effect legislation.

Each of the 16 centers across the country then had a mimeographed local news publication. The only one that was national was the Gazette which I was editing as a volunteer at Tommey Pavilion, the Cleveland respiratory center. In 1959 and in 1960, the Gazette organized its readers around the country from all of the centers to try to effect national attendant care legislation by writing to their congressmen. But we were ahead of our time, and we were too

naive politically. All we got out of it was a study by the Department of Health, Education, and Welfare (Nagi, 1962).

A Voice from the Past to the Present

I want to read excerpts from a memorandum, dated August 1960, which will seem to have been written for this conference. It was written by the late Dr. Leon Lewis, Medical Director of Fairmont Hospital, the San Francisco area regional respiratory center. It was written to Dr. John Affeldt, who was then Medical Director of Rancho Los Amigos Hospital.

In August 1954, the first financial grant from the National Foundation started the Fairmont Respiratory and Rehabilitation Center. During the six years of its operation, virtually everyone, no matter how severely paralyzed, has been sent home.

The combination of adequate financial support, understanding, cooperation, and a single goal of maximum rehabilitation has demonstrated that there is no disability too great for modern science to ameliorate.

The experience in one field of disease has shown the way to change the dismal picture of chronic illness in every field of medicine.

The cost of care has been remarkably borne by the National Foundation for Infantile Paralysis. This kind of financing is clearly of stopgap nature since it is inconceivable that any voluntary organization could continue to underwrite such expense.

The State of California should take measures to establish at least two regional centers, not only for respiratory paralytics from poliomyelitis, but from other diseases such as multiple sclerosis, muscular dystrophy, ALS, et cetera.

It is very significant that Dr. Lewis did not include spinal cord injury on his list, but 21 years ago, not many high level "quads" were around. If there had been, there would not have been the tragic

hiatus between the demise of the regional respiratory polio centers and the creation of the regional spinal cord injury centers.

A Successful Campaign for Attendant Care in 1960 in California

Throughout 1960 Dr. Lewis led a vigorous campaign, along with the polio survivors of the San Francisco Bay area, to effect attendant care legislation in California, and they were successful. By December the laws had been changed so that those on "Aid to Totally Disabled" could receive \$150 to \$300 a month for an attendant, depending on the disability and financial need.

Success by an Important Process

That 1960 campaign is very important, not only because it represents the responsibility of the government to provide attendant monies and regional centers, but because the legislation was effected by the combined efforts of medical personnel and disabled individuals.

Here, today, at this extraordinary gathering, we have the same combination of medical personnel and disabled individuals from all over the United States, from Europe, and from Canada to learn from each other's experiences and to solve together the common problems of all who are severely disabled.

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Resources

Until a structured network of information is created, those listed below will be helpful or be able to suggest someone nearer to you who can help with polio-related or respirator problems. Further,

if each of you will share your own experiences and your experiences with doctors and hospitals that understand polio survivors and respirator-users, the Gazette will organize them and continue to coordinate a people-to-people, do-it-yourself network. Call (314) 361-0475 or write to 4502 Maryland Avenue, St. Louis, Missouri 63108.

USA

If your problem is respiratory, start with the nearest LIFECARE representative, who will have had extensive experiences with polio survivors, doctors, and hospitals in your area.

East

Augusta Alba, M.D.
Associate Director
Goldwater Memorial Hospital
510 Main St.
New York NY 10017

Dr. Alba has arranged a special one-day evaluation program for polio survivors. Call (212) 750-6777 between 3:00 p.m. - 5:00 p.m.

LIFECARE Services, Inc.
165 Beale Street
Quincy MA 02170
(617) 472-4700

LIFECARE Services, Inc.
62-26 Myrtle Ave.
Glendale NY 11385
(212) 381-7018

Theodor and Shari Dukes
315 Ewing St.
Princeton NJ 08540
(609) 924-4512

Mid-Atlantic

Mary Jay Bullock, O.T.R.
Rehabilitation Medicine Department
The Johns Hopkins Hospital
600 N. Wolfe St.
Baltimore MD 21205

LIFECARE Services, Inc.
607 Beaver Court
Joppa MD 21085
(301) 679-0409

South

Ann A. Bailey, M.D.
Roosevelt-Warm Springs Institute
for Rehabilitation
P.O. Box 1000
Warm Springs GA 31830

LIFECARE Services, Inc.
2216 Mora Drive
Augusta GA 30906
(404) 738-3235

LIFECARE Services, Inc.
706 E. Curtis - Space E
Pasadena TX 77502
(713) 473-1840

R. Edward Carter, M.D.
The Institute for Rehabilitation
and Research
1333 Moursund
Houston TX 77030

Deborah Cunningham
1177 Poplar Ave.
Memphis TN 38104

Midwest

LIFECARE Services, Inc.
2 W. Wilson St.
Batavia IL 60510
(312) 879-1822

LIFECARE Services, Inc.
32486 Center Ridge Road
North Ridgeville OH 44039
(216) 327-2161

LIFECARE Services, Inc.
27133 Grand River
Redford MI 48240
(313) 538-0145

LIFECARE Services, Inc.
775 Leonard Street NE
Grand Rapids MI 49503
(616) 456-5003

LIFECARE Services, Inc.
621 Martha St.
Omaha NE 68108
(402) 345-4328

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Ann Arbor MI 48109

Anthony E. Lies
1140 Hilcrest Rd.
South Bend IN 46617

North - Northwest

LIFECARE Services, Inc.
2269 Ford Parkway
St. Paul MN 55116
(612) 699-2272

LIFECARE Services, Inc.
300 120th Avenue NE - #2-104
Bellevue WA 98005

Theda Carle
2615 4th Ave. - #602
Seattle WA 98121

West

LIFECARE Services, Inc.
13525 Wild Oak Dr.
Colorado Springs CO 80908
(303) 825-6118

LIFECARE Services, Inc.
11552 Knott Street - #8
Garden Grove CA 92641

LIFECARE Services, Inc.
421 N. Buchanan Circle - #9
Pacheco CA 94553
(415) 676-1176

LIFECARE Services, Inc.
19131 W. Whitton Ave.
(Rt. 1 Box 310)
Litchfield Park AZ 85340
(602) 935-0616

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Toronto, Ontario
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Joseph M. Kaufert, M.D., Ph.D.
Department of Social and
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University of Manitoba
750 Bannatyne
Winnipeg, Manitoba
Canada R3M 0T5

Gary McPherson
Aberhart Hospital
11402 University Ave. - #7127
Edmonton, Alberta
Canada T6G ZJ3

GREAT BRITAIN

Geoffrey T. Spencer, M.D., F.F.A.R.C.S.
Phipps Respiratory Unit
South Western Hospital
London SW 9, England

Dr. Spencer has created and directs a hospital unit and a comprehensive home care service system of medical management and equipment maintenance for 280 persons of all disabilities who are dependent on respirators. He has vast experience and concern to help respirator users living or traveling in western Europe.

DEFINITION AND SCOPE OF THE CRISIS

Allen I. Goldberg, M.D.

Medical Director, Division of Respiratory Care,
Department of Anesthesia,
Children's Memorial Hospital, Chicago, Illinois

Assistant Professor of Anesthesia and Pediatrics,
Northwestern University Medical School, Chicago, Illinois

Today, children remain in hospitals for years, dependent upon technological support devices to live. Today, polio survivors are older and concerned about the significance and possible uniqueness of their aging process. The quality of life as well as survival itself is, for many people, at risk.

The resources that are available are not being utilized to provide services for the unmet needs of disabled persons. Available knowledge and experience are not being disseminated or applied for their benefit. This is why we have today a health-care crisis. It represents a challenge and an opportunity for us to work together to change the situation.

The focus of this conference is to meet two needs:

1. The need to know more about the effects of aging in polio survivors and, along with that, to deal with the present lack of services required by people who survive by the use of technical aids.
2. The need to learn how we can meet today's health-care crisis and plan for the challenges of tomorrow.

* * * * *

I want to thank Dr. Henry Betts and Gini Laurie for hosting this meeting. You have brought us all together to approach health-care problems today the way every one of the polio survivors approached

these problems in the past.

Description of a Crisis

I am a pediatrician. Every day I see children in hospitals, on mechanical aids for breathing and other technological devices, who are remaining there for years. The financial and human sacrifices are tremendous, and I do not know what to do about it.

Today the hospitalization of children for years in acute care settings is an issue of critical importance. Previously, when expert intensive care created a generation of survivors who depended upon technical devices to live, new solutions, including home care, were found (The Philadelphia Enquirer, September 24-26, 1978). The home care concept was eventually extended to other areas (People, July 16, 1979), and recently it was made a national health-care issue by President Reagan (The New York Times, Presidential Press Conference, November 11, 1981).

The facts are: (1) Regional acute intensive care resources are denied to those who require them because they are being used to serve chronically ill children. (2) Health-care costs for this inappropriate setting are far higher than in a home or home-like setting. Currently, care for such children averages \$800 to \$1,200 per day. This care can be provided

safely at home at a two-thirds cost reduction initially, which further decreases with time as the children return to full health. The experiences of Britain and France with adults in the last two decades confirm this. (3) The number of children who could be at home but are presently in institutions represents a major health problem (Chicago Sun-Times, January 22, 1982).

My search for an answer to the crisis led me to Gini Laurie. For us, the International Year of Disabled Persons has been happening all year! When her plan for this conference was revealed to me, we worked together all during 1981 to create these three days we shall now spend together. We hope to address the crisis which we understand to be facing us.

The learning began from the instant we planned this meeting. It continues every moment we are working together, both within these rooms and outside. I hope it will lead to actions that will permit us to work together for years to come.

The Issues for this Conference

There are so many issues that we could discuss, as everyone in this room is an expert in more than one way, but we have focused this meeting on two objectives. One is your need to know more about the effects of polio with aging. We who provide the care also want a better understanding of what is happening to you who survived the epidemic of polio. The other need is to learn from you -- the health-care providers, the consumers, and those organizations that provide services -- how we can meet today's health-care crisis to provide services for the special needs of people. The quality of life as well as the survival of many people are at risk. Available resources are not being

utilized; available knowledge and experience are not being disseminated or applied for the benefit of people. We have again a new opportunity to work together as you did in the forties and fifties to solve the crises of the past.

The Process of the Conference

To truly work together, we will need flexibility. At the end of each session, we will outline definitive action proposals that we can take from this conference, actions that we can translate into a program concept. Already, by assembling this group to work together, we have proven against all doubts that we can and will solve any complex issue.

The Objective of the First Session - Focusing Upon the Past Crisis

To enable us to reach our session's objective, we will examine the crisis of the fifties and the way in which your multiple needs were met. To do this, we have divided the perspectives into those of the health-care personnel, the consumers, and the service organizations. We have selected one person to present ideas and another who will react with thoughts that represent views from each of the three perspectives.

Care for Life

Several members of the Planning Committee, Editorial Board, and some participants at this symposium are representatives of Care for Life. This not-for-profit organization was incorporated in 1980 to provide the needed services for people who depend upon technology for survival and quality of life. Care for Life considers this meeting a contribution to the International Year of Disabled Persons to increase public awareness for the vital challenges of the future.

HEALTH-CARE DELIVERY PERSPECTIVE

David Dickinson, M.D.

Former Medical Director (1950s),
Ann Arbor Regional Respiratory Care Center

Chief, Clinical Affairs,
University of Michigan Hospital, Ann Arbor, Michigan

The response to the polio crisis of the 1950s was a multidisciplinary approach that included funding, applied research, and technological and organizational advances. The need to develop regional centers was evident from the poor quality and the expense of care being given to countless isolated cases.

The state of the art of respiratory care in the fifties was in its infancy. It grew dramatically through principles learned from rehabilitation medicine, pulmonary physiology, and basic science research. The results were new developments in applied technology, new health-care organizational models, and great improvement in care.

* * * * *

What We Knew About Polio in the Mid-1940s

I am a pediatrician by training. I went to medical school at the University of Michigan in the mid-1940s, and I would like to tell you some of the things we learned about polio then.

We learned that polio had been around for centuries, probably since the days of the Egyptian pharaohs. Until the late 1920s, polio was a relatively rare disease of infants which sometimes caused paralysis of one extremity.

Polio was thought to be caused by a

virus. Every now and then there would be a case or two of devastating paralysis in individuals whose death would result from respiratory failure. There was a fellow named Phillip Drinker in Boston, Professor of Engineering at the Harvard School of Public Health, who thought he could build a machine to help these people. Phillip also had a distinguished brother, Cecil Drinker, Professor of Physiology at the Harvard School of Public Health, who was considered an expert in respiratory physiology. Phillip consulted Cecil, and Cecil told him that a machine would be of no help. Phillip built it anyway, and it did in fact save many lives during the early 1930s and the 1940s.

It was apparent even in the mid-1940s that changes were occurring and the incidence of polio was increasing. The extent of the paralysis was becoming generally more severe, and it no longer affected only infants. The susceptible age seemed to be inexorably moving upward year by year.

We had a rather distinguished epidemiologist visiting during my clinical years at medical school, and he talked to us for an hour. I don't remember anything he said except one statement: that there probably would never be a vaccine for poliomyelitis because the disease was not important enough. How wrong he turned out to be.

Polio During the 1950s

When I finished my pediatric training, it was 1951. My chairman, Dr. Jim Wilson, had been chief resident in pediatrics at Boston Children's Medical Center. Phillip Drinker was then using his respiratory machine in a couple of nearby Boston hospitals. Dr. Wilson put the first child in the iron lung. He had been a dear friend of the March of Dimes, and they were very anxious for him to start a respiratory center in Ann Arbor. I had rented an office to practice pediatrics, but Dr. Wilson talked me into staying and running that regional respiratory center.

The Polio Crisis of the 1950s and the Response to It

The epidemics of the 1950s were indeed terrifying and devastating, and posed a threat to populations worldwide. A disaster of that magnitude can have a few useful side effects. Money was pouring in for any reasonable effort, and people from many disciplines both within and without the health professions were beginning to apply their skills and knowledge to this problem.

In a sense, the iron lung capped the dilemma we were in. By saving a lot of people from dying, it forced us to deal with the problems of appropriately caring for those who lived.

The Research on Polio

There was a lot of interesting and important research going on in those days. Much of it was made possible by the Nobel Prize-winning efforts of Enders, Robbins, and Weller, who were the first to successfully grow viruses in tissue cultures. No longer did we have to import expensive monkeys and do three experiments in three months. We could grow literally tons of virus and tissue cultures and do many more things.

We were very sure in those early days

that the major route of polio transmission was by fecal contamination, and perhaps by droplet infection. We knew it entered the central nervous system but did not know how. Theories favored viruses that went up the nerve trunks, although they really should then have spread throughout the bloodstream. Nobody could demonstrate the theory until finally it was determined that there was a transient bloodstream infection at a very early stage of the disease.

All of these virus cultures disclosed other interesting results. We had always thought that the majority of polio patients, even those with central nervous system involvement, did not become paralyzed. The reason was that many patients with positive spinal fluid signs of meningitis did not have paralysis. When researchers started culturing everything in sight, during epidemics in this and other countries, we discovered viruses which had been known for decades to have caused other diseases. Most of the non-paralytic polio meningitis was actually caused by these other viruses.

The Need to Develop Regional Respiratory Centers

Interesting as this was, it did not help us very much in treating patients.

We were very excited when we started the first respiratory center in our area of the country. Respirator patients had been collecting by ones, twos, and threes in community hospitals everywhere. We wanted to bring them to the center, but we did not know how to transport them. Finally, we got a big truck with a power lift tailgate, bolted an iron lung to the side of it, and installed an electric generator that was left over from a World War II field hospital. We got a good nurse, an engineer, and a very young physician, and we went and picked up the patients.

The environment we found them in was amazingly consistent in these various hospitals. Usually they were in a quiet,

dark room with lots of flowers around. The patients had received a lot of tender loving care from their nurses and their physicians, but most of it was rather inept. If that seems a little harsh, we were just about as inept as the rest of them. But, we set about trying to figure out how to treat these patients a little more systematically.

The State of the Art of Respiratory Care in the 1950s

Some things we did know about respiration. That there are chemoreceptors and that carbon dioxide concentrations and oxygen tension are important in regulatory mechanisms had been known for many years. What we lacked were the appropriate tools for measuring the carbon dioxide concentration and the oxygen saturation.

Another thing we had not paid much attention to, and hardly any clinicians knew anything about, was the mechanics of breathing: that is, how the muscles really worked in creating respiration and how they were related to the control mechanisms. We knew nothing about long-term artificial respiration. Everybody knew how to do it for half an hour or an hour, but we did not know anything about how to do it, and do it right, day after day.

We learned from our physical medicine friends and respiratory physiologists a little bit more about motor nerves, muscle fibers, and motor units. For example, we learned that, when a muscle contracts at much less than its maximum effort, only a few fibers are firing; then they rotate around while the remainder of them rest. If the fibers are not rested often enough, they become fatigued, and then they do not work any more.

We also knew that in respiratory paralysis and polio, many of the motor units were knocked out. The whole work load was borne by the remainder of the motor units, which meant they were working

much harder than they were accustomed to for a given amount of muscle contraction. Consequently, they became fatigued from overwork.

About that time, we also learned a rather terrifying fact: during acute and early convalescent poliomyelitis, if one overworks a muscle, the paralysis gets worse, and, in fact, one could make it permanently worse. Most of that research was done with monkeys, but it was confirmed by human patients who were ineptly treated during those days. If you couple that with the rather common practice of telling the respirator patient that if he practices hard enough and is "gutsy" enough, he can get out of a respirator, you can understand what a terrible non-scientific start we had.

Technological Advances in the 1950s

Once we learned how to do things reasonably right with the iron lung, we had the dilemma of people who were now very anxious to become functional and useful and were encased in a tin can. Fortunately, we were rescued through the efforts of many people who developed the cuirass respirator, the rocking bed, and the little cosmetic case with the exhalation valve built out of a tin top from a maple syrup can. I notice they are still using this in a similar size but without the exhalation valve.

Organizational Advances in the 1950s

Our next problem was that of becoming rehabilitation centers. Fortunately, physical medicine, which was just then being born, developed the kind of team effort by both health and nonhealth professionals that enabled the next stage of care to go forward. If I had not talked so long about nostalgic history, I would like to say some things about how tough it was for people to leave that protective environment and to survive at home. But you know about that.

You know that our biggest problem right now is to do something about the hostile world that pioneers have to survive in and to further improve the lives of a lot of people who have major handicaps. You have demonstrated that you can lead useful lives and become productive citizens. You are pioneers. You are an integral, critical mass of experienced people. We do need you. I have to say I

am proud to know you.

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REACTOR: HEALTH-CARE DELIVERY PERSPECTIVE

Augusta Alba, M.D.

Director, Howard A. Rusk Respiratory Rehabilitation Center

Associate Director, Goldwater Memorial Hospital

Associate Professor of Neurology and Rehabilitation Medicine,
New York University School of Medicine, New York, New York

Unique circumstances fostered the development of the Howard A. Rusk Respiratory Rehabilitation Center at Goldwater Memorial Hospital in New York City. The initially unfavorable location and status proved to be the very reasons for survival after private funding sources ended.

The evolution of the original polio-respiratory experience at Goldwater, improved with additional resources from rehabilitation medicine and pulmonary medicine, led to the modern respiratory rehabilitation now available in New York City. Synthesis of the expertise, interest, and resources at Goldwater has made possible a center offering much broader services than those available in the days of the polio epidemic. Today's services include respiratory rehabilitation, stress/exercise evaluation, home ventilation, and home attendant care concepts for the ventilator-dependent person.

* * * * *

Introduction to Respiratory Rehabilitation and the Regional Respiratory Center in New York City

Dr. Dickinson came from the field of pediatrics. Fortunately, I came from the field of neurology into rehabilitation at a time when polio patients needed that area of expertise.

I was training at the Veterans Administration Hospital and had my first respiratory patient with Lou Gehrig's disease. I saw him breathing like a feather and didn't know what it was all about. I sent for respiratory studies and found that he was living with practically 5% of his vital capacity. I didn't know how to treat him, and neither did anyone around me.

That was about 1953. The last part of my residency was at the Goldwater Memorial Hospital, in the Respiratory Rehabilitation Center, which was then one of the regional centers for poliomyelitis. I fell in love with the place and have been there ever since. For those who wonder how you can stay so long in one place, I have always felt you stay where you are if you can still build something bigger and better than it was, and that is exactly what we have been able to do there.

In retrospect, Dr. Rusk may have been farsighted in his placing of the regional respiratory center of New York City in what was considered a long-term chronic disease hospital on Welfare Island. You couldn't have worse connotations than that! But it actually was the right way to do it, because people did not belong in the acute contagious disease hospital after getting over the acute phase of poliomyelitis. They belonged in long-term rehabilitation. Later, we were

lucky in being able to keep our center, mainly because we received funds from the City and the State of New York and from the federal government, whereas many other centers, dependent upon voluntary funding, were forced to close.

The Evolution of the Howard A. Rusk Respiratory Rehabilitation Center, Goldwater Memorial Hospital

What happened to our center? It changed its mission. From having all polio patients, a census of 80, our center shrank very rapidly when the vaccine came along. Later we started growing again. Our polio patients now represent about one-quarter of our total population. To that we have added the whole list of neuromuscular diseases, the treatment of which has benefited from what we learned about poliomyelitis and ventilation. Also at Goldwater we have a large number of intrinsic lung disease patients, especially chronic obstructive lung disease, people who can no longer live at home. We have two or three wards of that type of patient, many of them on long-term ventilation, who have also benefited from what we have learned in caring for the polio patient.

When our Respiratory Rehabilitation Center was separated, it was considered a "Cinderella," the stepchild; the rest of rehabilitation medicine at Goldwater Hospital was the "mother" and the polio center itself was the "regular daughter" of the Cinderella tale. When the National Foundation stepped out of the supporting role, our center became integrated into the rest of rehabilitation. Then both rehabilitation services benefited from the sharing of services and the sharing of knowledge.

Other Beneficial Programs from the Howard A. Rusk Respiratory Rehabilitation Center

At Goldwater, a pulmonary function laboratory developed with monies from

the National Foundation. This laboratory remained within the Department of Rehabilitation. Our laboratories now include a "work physiology" or "work capacity/cardiac stress/exercise laboratory," in addition to an EMG (electromyography) laboratory. We have these integrated rehabilitation medicine laboratories as a direct result of our initial polio center.

As Dr. Dickinson pointed out, patients did not want to stay in lovely private rooms on acute contagious disease services with flowers and good nursing care. They wanted to go to a rehabilitation center. For example, a young man by the name of Ira whom we sent home just could not live there. Home for Ira and many others meant isolation and the denial of an education. You couldn't go to college from home in those days.

Since Ira lived in Nassau County, it was suggested that he be sent to Meadowbrook, a county hospital, on the pediatric service in a private room. Ira said, "That's not for me!" He was able to fight the authorities and return to New York City, to the Goldwater Rehabilitation Center, to live. Nassau County had to pay New York City for him to be there. As a result of being there, he was able to finish his high school education and go on to college by way of an "Executone telephone system," defunct for about 20 years, which we resurrected at that time for him.

He married another polio patient and was able to leave the Goldwater Hospital to live at what is now called "Island Town" next to Goldwater on Roosevelt Island. Island Town is a housing development for 2,500 families, of which Goldwater residents are entitled to 25 apartments for use as independent living arrangements.

Ira is now out in the community, but that is not the end of the story. He went ahead and developed "Concepts of Independence for the Disabled, Inc.," a client-maintained plan which provides home attendant care for the independent disabled

consumer in the community (Concepts of Independence for the Disabled, Inc., 853 Broadway, Suite 1920, New York, New York 10003, (212) 673-3373). At the present time, Ira's organization has a contract with the Human Resource Administration of New York City for \$3 million to provide vendorized attendant care for disabled persons living at home. [The implication of his type of disability can be read in Arthur Haley's book, Overload. -- Ed.]

As a result, in New York City, we have been able to develop, with the aid of monies from the City and the State of New York, one of the most comprehensive services for respirator-dependent people in the country. We still are far short of some of the services people need. Some of that will be discussed later in the conference by Alice Nolan, a rehabilitation nurse who has gone into the community and visited at least 85 of our people who are severely disabled. She has prepared and administered an independent

questionnaire and conducted interviews from which she is now collating data.

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CONSUMER PERSPECTIVE

Ronald Doneff, M.D.

Practicing Dermatologist, Merrillville, Indiana

Contracted polio during senior year at medical school
and is ventilator-dependent

Those who have survived polio now find that no one is equipped to handle their present needs for services and care. Polio survivors need to be recognized as a group. The situation has reached crisis proportions for the high-level spinal cord-injured person who urgently needs respiratory care and other support services.

Recommendations for action are to disseminate existing information; increase public and individual awareness of the issues involving the disabled and their needs; and create a multidimensional funding base.

* * * * *

A Past Encounter Among the Participants

Until almost this moment, the only people I knew at this entire gathering were Gini and Joe Lauri and Dave Dickinson. I met Dave 26 years ago, when I was sent up to Michigan from Indiana where I was a medical student. When I arrived at the ward, he came over and introduced himself. I had a "trach" tube, and he said, "Do you need that thing?" I said, "I can't stand the damned thing." With that, he picked up a pair of scissors, cut the neck cord and yanked it out. I have been indebted to him to this day.

The Issue: Polio Survivors Have Survived and No One is Equipped to Handle their Care and Needs

I want to thank Dr. Betts and Gini for

laying a very nice groundwork for this meeting. In essence, it answers the question of the meeting. We are all still out there and here! Somehow we have to get back to the multidisciplinary institution or center, or whatever it is going to be, to manage our problems.

As I look around here, I don't see a lot of people with respirators. There is a handful of us, and we represent, I think, the area of greatest crisis today -- the transition from acute to long-term care. This is my understanding, though I could be wrong. Nobody is equipped to handle people with respiratory paralysis!

Maybe this sounds kind of haughty. Because I have attempted to live in the "normal" world, I do not associate with a lot of disabled people. I do not like forming cliques which have in common only an affliction. By the same token, I resisted people's efforts to direct me back into research specifically related to my problem. I do not have any use for an attitude that says, "Go out and get the disease that got you."

The idea of striving for recognition as a group of polio survivors is a new one to me. Yet we do need it desperately. I feel apologetic in saying that I was not so sure how much we needed it. Most of us have come this far in one way or another. But there are many, many people who have no inkling that they will be like us one day all too soon, and they are the ones who have nothing at the moment to go for.

A Modern Crisis - High Level Spinal Cord Injury

I just came back a month or two ago from visiting a young man in an Indianapolis hospital who sustained a C-4 fracture and cord transection in an auto accident. I am sure that auto accidents must be the number one or number two cause today of disabilities leading to respiratory insufficiency and dependence upon a breathing machine.

This young man was 24 years old. He had been brought in with a lot of broken bones and so forth, and these were tended to, and that was it! He was lying there. He had decubiti, which most of you, I am sure, will agree is unforgivable. He was in an intensive care unit, being taken care of by the Neurology Service with Rehabilitation only consulting.

It is hard to believe this part of the story. He was told how terribly expensive his life and care would be. His family was told that he really had no hope, that he would be a miserable vegetable for the rest of his years -- not a vegetable in the sense of not having a mind, but vegetating. He was actually offered the option to die. Thank God, he had an ICU nurse, who had enough spunk to go over the heads of the faculty. I think she contacted Gini first, then she called me one night, and, as a result of her efforts, he has finally been transferred out. Except for this girl, he would still be living (or dying) there!

Disseminate Information

One of the most important things we can do, if not the most important, is to disseminate information. We know that Dr. Alba, Dr. Dickinson, and many others of you in this room have specific knowledge, but other doctors, consumers, and organizations do not know you have that knowledge. They do not even know you exist. Somehow we have to get the word out that there is a place to send these people!

To the best of my knowledge, there are few centers in the United States that can handle a respirator patient in the rehabilitation phase. I do not know for a fact that the patient from Indianapolis is dead-ended, but I was told that even the Rehabilitation Institute of Chicago cannot handle him. Instead, he has to lie there until, maybe, by the grace of God, he gets enough respiratory function to sit in a tub without drowning. Rehabilitation will never be started! The young man from Indianapolis did not even know he could sit straight up! He had not spoken a word in four months. Nobody ever told him that he could plug the "trach" tube and talk! Anyway, we have to get this information out.

Increase Awareness

I do not like militancy. I am even a little offended by the notion. When someone says to your wife or to your attendant in your presence, "Does he want coffee?" it is a normal reaction to experience that as a terrible affront. Do you know how to act in front of someone who is different? Deaf, blind, cerebral palsied? It's awkward. People have no malice toward us; they are simply ignorant of us. And yet, I find that people accept me and, I am sure, all of you very graciously, one-on-one.

I am practicing dermatology every day, and one of the nicest things that happens to me is when a patient walks into my office and is totally dumbfounded at my physical state. Nobody told him! And I think how great it is that his friends did not tell him, his doctor didn't tell him, and the patient is not uncomfortable in my presence. When I go to restaurants, people do not find me offensive. On the contrary, they are very helpful, sometimes too helpful.

Obtain Funding

Somehow we have to get funding for respiratory rehabilitation centers. When Roosevelt died and the polio vaccines

came along, the big numbers were gone. I do not know how you gain contributions for smaller groups of people, but I believe that the human potential can be realized without question if the physical apparatus is available. The afflicted can become taxpayers once again. We can show people that a fellow who is put back to work contributes a lot more than he would take out if he were left disabled in his bed. [For every \$1 spent on those disabled persons who returned to society as taxpayers, \$7 is returned to society. -- Ed.]

Those of us who have contacts should go after congressmen, businessmen, and others. There are many ways to bring people over to our side. Perhaps we ought to organize some lobbying and try to

obtain tax breaks, not only for ourselves, but for those people who hire us. A lot of people don't know that vocational rehabilitation still exists. Vocational rehabilitation needs to be thought of as an investment that will be returned to society as disabled people return to fully functioning lives.

A Consumer Viewpoint

Either Dr. Goldberg or Dr. Betts said something about our having solved the problems that came up in the 1950s. I am not sure who solved them. I think we were dumb enough and lucky enough to muddle through them. Some of us, obviously, did make it through, but a lot of us did not. More than solving the problems, I think we were just lucky.

REACTOR: CONSUMER PERSPECTIVE

Jack Genskow, Ph.D.

Professor of Rehabilitation,
Sangamon State University, Springfield, Illinois

Contracted polio, 1955, while a sophomore at Yale,
later earned his doctorate at the University of Illinois

This very personal account describes what it was like to become disabled with polio during the epidemics of the 1950s and the important role the regional respiratory centers played in saving lives. The conventional hospital simply was not equipped to minister to the special needs of polio patients. Only in the newly-formed respiratory centers was high-quality treatment available. These centers provided good equipment and an effective staff with the personal qualities necessary for long-term treatment. They also offered an opportunity to cultivate peer relationships which was as important as the support of family and friends.

* * * * *

I want to commend the planners of this conference. I especially like the Dickensian format of past, present, and future. I feel like one of the ghosts of epidemics past.

Dr. Doneff has presented some stimulating thoughts. One perhaps obvious but terribly meaningful point bears repeating: there were a lot more of us in the past than there are now. As I prepared for this conference, looking back through time, I realized how many of the good people that I have known who fought the valiant battles of the mid-1950s with polio are gone. A lot of us are still around, and that is why we are here today, to tap our knowledge and resources and to plan our future actions.

What Was It Like?

How does one communicate the experience of the polio epidemics of the 1950s? How can one communicate a roomful of iron lungs whooshing in and out? Remember that?

What does it mean to become totally dependent even for breathing when one is used to being very independent, or, as in my case, going from 165 to 95 pounds, when I used to be proud of my physique?

What about seeing the shock and discomfort in the eyes of visitors when they first saw you? How about sharing your iron lung on a hot day with a fly that tickled? Or how about getting 50 Christmas cards in one day? That social support was fantastic.

A Personal Experience

Remembering those experiences, I thought that perhaps the best way to comment on those days was to describe briefly my own personal experience. The summer of 1955 I was 19 and had just finished my freshman year at Yale. I was working at a summer job as a riding instructor at a girls' camp.

My first encounter with the health-care system was with a headache and stiff neck, then pain in my legs. When I saw the doctor in this resort town in central

Wisconsin, he gave me aspirin, said I had the flu, and sent me home. The next day I was back, but to a different doctor. He said, "Well, you are recovering from a mild attack of polio, but maybe you ought to go down to the hospital and get checked out."

I remember the ride down to Milwaukee and entering the hospital. They gave me a spinal tap and confirmed that I had polio, which did not have much meaning to me. They also said I would have to lie flat on my back for 24 hours so that I wouldn't get a headache from the spinal. I could not imagine the possibility of lying flat for 24 hours. That seemed a long time in my active life -- but it was 2½ months before I sat up again, and then in a rocking bed. It was 20 months before I got out of the hospital. I was 21.

The hospitals I went to included an acute care center, a county hospital, a private hospital, and finally respiratory centers in Omaha and Chicago. I could not get into the Chicago respiratory center in 1956 because that was the epidemic year, and the center was full. But I remember Milwaukee County Hospital where the battle was to get out of the iron lung. The iron lung was warm, comfortable, and breathed for you. It did all the work for you. It was kind of like an iron womb. I remember reflecting later that the experience was like being born again, a difficult birth, but when you came out, you were somehow a different person. You were not really, but it seemed that way at the time.

I went to my brother's farm after leaving the hospital, and there I had a good transitional experience. I had one

acute episode with intestinal blockage and went to a local hospital. They had no idea what to do with me. I just lay there puffing up bigger and bigger and nearly dying until finally they got me to the Chicago respiratory center. There, in a matter of minutes, the doctors passed a mercury-weighted tube down into my intestine, drained off the accumulated liquid, and in a very short while I was okay. The important point is that the usual hospitals and medical staff often did not know what to do with polio patients. The specialized centers did.

I want to comment briefly on those special respiratory centers because they had excellent medical treatment and equipment. I was lucky enough to be in two of them. The staff was effective and had the personal qualities that are necessary for long-term treatment and extensive therapy. The centers provided a chance to be with people one's age who were going through similar problems.

I want to mention how important the support of family and friends was. While the centers had a number of special programs, the Chicago respiratory center provided two especially important events for me. One was a trip to the University of Illinois in Urbana with a doctor and a physical therapy nurse, which is not on the usual hospital program but opened the door for me to get in there later as a student. They also gave me a pass one night to go on a date with a nurse from another floor whom I had met two years prior at another hospital, and the relationship which began that night has lasted about 23 years. My wife is certainly the major part of my rehabilitation and my life.

ORGANIZATIONAL PERSPECTIVE

André Dessertine

Magistrate, Creteil, France

Former President, World Veterans Association

President, ADEP (Association d'Entraide des Polios Handicapés)

Invited guest of the U.S. Congress, 1976

Recipient of the Legion of Honor for service
to the disabled community of France

Contracted polio, 1962, in Paris and is paraplegic

The dismal outlook the polio survivor had to face before World War II contrasts markedly with the pioneering progress that has been made in France since 1945. The most noteworthy accomplishments for disabled people to date include:

- . Garches, France (1949): The Respiratory Rehabilitation Center (Bréznin Pavillon) and the Reeducation Program at the Hospital Raymond Poincaré.
- . ADEP (1961): The creation of a disabled advocacy movement providing vital services to benefit the polio survivors. The effort was initiated and led by the polio survivors at Garches.
- . ADEP (1981): The development of the organization to provide the services necessary for all disabled individuals to return to society. It includes a documentation center, a home ventilation program, and independent living centers.

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[Mr. Dessertine apologized for speaking in French. His commentary was translated by Dr. Goldberg as follows. -- Ed.]

I want to thank all of you and give you best wishes from the disabled people in France, including those who had polio. Dr. Goldberg has asked me to speak about what we have done in France for polio patients. I will talk a little about the past, because to understand the present one must look at the past.

Earliest History of Polio in France - 1925-1945

I will begin in 1925 which, for us, is really time zero. It was considered "zero" because polio was a disease that had a minimum of mortalities -- only 5 per 100,000 -- and it only affected children, which is why it was named "infantile paralysis."

There are three major aspects of polio: its prevention, its treatment, and the reintegration of the polio survivor into society. In the early days, there was no thought of prevention, because no one quite knew the origin of the illness. Nor was there treatment, because there was no rehabilitation and no orthopedics at that time in France. If someone had polio, there was really no solution whatsoever if he did not have a family to take

care of him. There were, it is true, hospices which had been in existence since 1925, but these were little more than prisons.

There were, however, activities to benefit the disabled during the early years. But it was the handicapped people themselves who began to take charge of their own treatment. Organizations and associations were started to bring together the disabled so that they could work together on their own behalf. After World War I, many handicapped veterans became the beneficiaries of these services. The associations of the severely disabled focused upon social reintegration and their activism did much for their own cause.

Polio in France after 1945 - The Respiratory Rehabilitation Center at Garches

What finally drew interest in polio was the sharply increased number of cases after World War II. Prior to then, only Switzerland, which had a big epidemic, showed any real interest in polio.

In 1949, a center for the treatment of polio was developed in Garches, France, at the Hospital Raymond Poincaré. At Garches, a concentrated team began to approach polio as never before. For the first time, services such as physiotherapy, occupational therapy, respiratory care, and reeducation were integrated into a total program. Professor Grossiardi, a neurologist, was one of the founders of this effort and the founder of rehabilitation medicine in France.

Garches played a unique role in the development of respiratory rehabilitation in France. Prior to World War II, anyone with polio or respiratory disease was virtually condemned to death. Later, technological advances such as the iron lung and tracheostomy made possible the organization of respiratory rehabilitation programs.

The present patient population at

Garches includes infants, children, and adults with polio and other serious motor disabilities, including respiratory insufficiency due to neuromuscular causes. There are four pavilions of Raymond Poincaré, one of which is the respiratory pavilion for children. Each pavilion can accommodate between 30 and 40 people. Three other divisions are designated for other special medical needs.

Today in France, Garches is the national center for the education of the disabled. The effort to educate starts at the preschool level and continues through pre-baccalaureate programs. Polio survivors at Garches have had this education in order to prepare to return to society. In addition to academic education, other activities of occupational therapists and other special educators prevent functional loss, so that individuals can make use of their fullest potential.

The Development of ADEP

The polio survivors at Garches played an essential role in the reintegration of the French disabled person into society. The early activities included creating accessible transportation and eliminating architectural barriers. Our organization, Association d'Entraide des Polios Handicapés, played the vanguard role for the entire disabled community of France.

ADEP's History

In 1961, a group of polio survivors assembled at Garches to meet their own social needs and to take steps for a return to society. Initially, ADEP's primary concern was with the conditions of life in hospitals, especially the difficulty polio patients were having in trying to leave hospitals. They wanted desperately to return to normal lives. The first steps were in working with the authorities to gain a temporary leave to return home. The next step was gaining permission to leave the hospital permanently to work, to go on vacation, etc. Additionally,

ADEP mobilized volunteers and community people to assist those in Garches to get outside and reenter the community.

After this, ADEP began the development of independent living facilities run by the people who were at Garches. These centers no longer exist because other solutions have been found.

ADEP Today

In 1981, other services have replaced the original activities which permitted

integrated independent living for respirator-dependent people. Now ADEP is involved with the issues of independent living -- accessibility, transportation, and home care -- not only for the polio survivor, but for all disabled persons, including those with respiratory disability. The most important development has been an information processing center, a center of documentation resources. With this information registry, practically any concern of a person, an association, or a group of professionals can be addressed. One can find through the center the information needed in the form desired.

REACTOR: ORGANIZATIONAL PERSPECTIVE

Audrey J. King, M.A.

Rehabilitation Psychologist,
Ontario Crippled Children's Centre, Toronto, Ontario

Contracted polio, 1952, in Oxford, England
Ventilator user, 1952-1959

The Ontario Crippled Children's Centre in Toronto was first conceived in the 1950s to serve the many post-polio youngsters who needed rehabilitation treatment. However, by the time the building opened, the vaccine had been developed and the population of polio youngsters needing acute treatment had disappeared. The case load today includes only a few, all of whom have come from third-world countries. In Canada, as elsewhere, the large rehabilitation centers and organizations active in current rehabilitation programs were originally started to help polio patients.

As a result of government-assisted immunization programs, the unique problems of persons who have had polio have somehow become minimized. These are the problems that need to be addressed, along with the generic problems of overall functional disability.

There is concern now that medical people have insufficient understanding or inadequate knowledge about post-polio-related issues. There is fear that orthotists can no longer make proper braces, and there is great difficulty in getting parts and maintenance for ventilators and other technological aids required by polio survivors.

Factual data about the early years of the polio epidemic are very scant, and, as the years go by, it becomes increasingly difficult to obtain reliable recollections. There are inadequate numbers of polio

survivors to generate interest by funding services to find solutions for the problems of polio survivors.

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The Ontario Crippled Children's Centre -- a name that is soon to be changed -- does not see many youngsters with polio. Our case load includes only a few who have found their way to us from third-world countries.

I think it is interesting to reflect on the comments made earlier, that all of the big rehabilitation centers and the organizations involved with current rehabilitation needs seem to have started initially because of polio patients. This is true for our centre, also. It was first conceived in the 1950s, because of the many post-polio youngsters who needed rehabilitation treatment. The vaccine was developed, and, by the time the building was opened in 1962, the population of polio youngsters needing post-acute treatment had disappeared. Thus, even our most permanent staff people could not assist me in my search for information about the epidemic years.

My search for information took me literally from one end of Ontario to the other and provided me with all kinds of ambiguous, confusing comments regarding what was done, who did it, and where the assistance began and ended. I collected statistics from the Ontario Ministry of Health and talked to several older

physicians, some of them retired. I contacted agencies such as the Ontario March of Dimes, and I interviewed a retired public health nurse on the far north-western edge of Ontario by telephone.

The Polio Situation in Canada during the 1950s Epidemic

The clearest data, as you might expect, came from the Ministry of Health. When you look at the Ontario polio statistics, you can appreciate that, as was the case in the United States, as the numbers of cases increased, people responded to the need.

Ontario was not as badly hit as Canada's western provinces. In 1953, which was the worst year for Ontario, there were only 928 cases in a population of 4.9 million people. That is 18.7 people per 100,000 population. In Manitoba, during that same year, there were 2,300 cases, or over 300 people per 100,000 population, a 16 times greater incidence than in Ontario. There were 93 iron lungs in one hospital ward at one time in Winnipeg, the capital of Manitoba.

In western Canada, greater resources, including home support programs, were developed, perhaps because their epidemics were more overwhelming. These services are still in existence, and, at least in Edmonton, Alberta, they include a super home-maintenance outreach program for respirator users. Those of us who live in Ontario are absolutely green with envy! We do not have any equipment paid for by the government as many other provinces do, and we certainly have no home respiratory maintenance program.

To go beyond the factual data, we depend upon people's recollections. Still, it is difficult to get a clear picture of what happened during those early years. One thing for sure is that there was no provincial health insurance plan to cover hospitalization bills as there is now. I imagine that many of you from the United States are envious when you look at those

of us north of the border who do have this system. There were no funded visiting nurses or homemaker services at that time. People who got polio and were left paralyzed were faced with major financial problems, particularly if they needed aid or equipment.

According to Dr. Albin Jousse, the retired Medical Director of Lyndhurst Lodge, Ontario's major spinal cord injury hospital, serious cases tended to be referred to major centers such as Toronto and Ottawa. The person who got out of the respirator went to Lyndhurst for rehabilitation. The patient who remained respirator-dependent was either transferred to chronic care or went home with respiratory equipment and home help provided, I believe, by the Ontario March of Dimes. Some 400 polio patients received rehabilitation at Lyndhurst between 1945 and 1955. An interesting comment which Dr. Jousse shared with me (I hope there are not too many spinal cord-injured people here) was that subsequent to rehabilitation, the polio survivors have tended to do a lot better than the spinal cord injured.

A public health nurse who was then very involved recollected that the provincial government provided the iron lungs and the equipment in the hospitals during those early years. The Society for Crippled Children (now the Easter Seal Society) was set up and supported by various service clubs, such as the Rotarians, to provide braces, wheelchairs, and other equipment for children. Government funding at various levels also helped out individuals, those designated "indigent," by providing braces and chairs through municipal and provincial welfare programs.

When the vaccine was developed, the Ontario March of Dimes launched huge immunization campaigns which the government eventually incorporated into their wide-scale immunization programs that exist today. As the Visiting Nurse and Visiting Homemaker programs came into existence, and as generalized funding-assistance programs were

established by the provincial Ministry of Health, the home care health support (which seems to have been provided on an individual as-needed basis by agencies such as the March of Dimes) gradually lapsed.

The Polio Situation in Canada during the 1980s

Much has changed over the last 30 years. Agencies originally set up to meet the needs of polio patients now incorporate all physical disabilities, in much the same way that the polio vaccine itself is now included with vaccination against other childhood illnesses. The number of polio survivors in Ontario was estimated last year by a provincial health survey to total approximately 5,500. But the difficulties they encounter, as well as the degree and extent of their disabilities, are not known.

I would imagine that the difficulties they experience are those of all the functionally disabled, regardless of the cause: employment issues, transportation issues, housing, independent living, and so on. The polio survivors in Ontario are involved in consumer activity groups within the mainstream of society in much the same way the other disabled are. Because of this integration, the unique problems faced by people with polio have become minimized over the years and not given the importance that I think is now required.

The Unique Problems of the Post-Polio Survivors Today

There are unique differences and problems experienced by older polio survivors. These need to be addressed in addition to the generic problems of overall general functional disability.

Some polio survivors in Ontario whom I have talked to are experiencing the premature aging problems already referred to in this conference. The

associated anxiety, stress, and emotional adjustments are sometimes as great as that generated by the original polio onset. There is concern that medical people today are ignorant of the problems faced by older polio survivors.

There is fear that orthotists can no longer make the braces older polio survivors are used to, and that people do not really understand what the issues are. For Ontario home respirator users, the exact number of whom I really cannot determine, there is difficulty getting parts, absolutely horrendous difficulties! Many people have had to find machinists to make obsolete parts for outdated equipment. There is tremendous difficulty getting a respirator serviced, for there is no coordinated home care service system. Individuals dependent on life support are literally on their own and must canvass their neighborhood, go through the Yellow Pages, or try to find somebody, somewhere, to help them get parts and repairs. I often think that if a person in such a situation ever became terribly depressed about his problem or did not have a good brain, more than average courage, and will to endure, he could not cope on his own any longer, as it seems he has to now.

Perhaps there were too few of us in Ontario, particularly those of us who use respirators. Not only do we not know how many respirator-dependent people there are, we do not know where they are. One Director of Respiratory Therapy in a major Toronto hospital told me there are just too few of us. He said they could do something about the problems if our population were larger. I sometimes have wished the epidemics had been larger so that we would feel less neglected in Ontario.

The Medical Director of the Ontario Thoracic Society thinks that most of the respiratory polios have died by now. A prominent Ottawa respirologist, in practice since the 1950s, said that she has only seen two or three polio survivors with respiratory involvement, and, in her

opinion, this was never a major problem. A volunteer minister, who once travelled through the province for the March of Dimes to repair units at home, believes that there are at least two dozen of us still in existence, but he's not sure where we are.

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- . Rev. Essex, Toronto, former March of Dimes volunteer respiratory technician.
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Rehabilitation Services, Kingston General Hospital (Kingston, Ontario) and Medical Director, Canadian Rehabilitation Council for the Disabled (Toronto).

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GROUP DISCUSSION

WHAT FACTORS LED TO A SUCCESSFUL APPROACH TO MEETING THE NEEDS OF POLIO PATIENTS?

Adolph D. Ratzka, Ph.D.

Research Economist, Royal Institute of Technology,
Stockholm, Sweden

Contracted polio as a teenager in Bavaria, Germany

Rev. Patrick Lewis, C.S.S.P.

Pastoral Care Counselor, Rehabilitation Unit,
St. Mary's Hospital, San Francisco, California

Contracted polio during the second year at Roman
Catholic seminary and is quadriplegic

Dr. Adolph Ratzka

We were asked to reflect on what factors led to a successful approach to meeting the needs of polio patients. What we have failed to do, though, is to set criteria for what we mean by "successful."

As a first, basic criterion, how many of us are still around? As was indicated by Jack Genskow this morning, most of the people we knew who had polio are dead. So, on this score, I think our needs have certainly not been met successfully.

As another criterion, I suggest the following. We have been talking a lot about the situation in rehabilitation centers and what has been done for us there. But how has it been outside? To what kind of life have we been released from the hospital? Have our needs outside the rehabilitation center been successfully met in the sense that we have been given the same degrees of freedom as everybody else? In that respect, again, I cannot share the optimism implied in the wording of the question, "What factors led

to a successful approach to meeting our needs?"

What we need to talk about here -- and I hope that we are going to address ourselves to these issues -- is how we can improve our conditions outside institutions. Man does not live by respirator alone. Nobody so far has talked about housing. How about attendant care, public transportation, accessible cities, possibilities for study and work -- everything, in fact, that makes life outside an institution worthwhile? We should focus on these issues.

Rev. Patrick Lewis

All the good things that arose in the polio era came from the fact that a crisis was defined and that polio generated an emotional reaction. This needs to be done again, particularly now in regard to the problems confronting people who have had polio in the past. Awareness of the particular phenomena needs to be developed and assistance provided.

What I am going to say is almost a duplication of what Dr. Ratzka has just said. I think the most important thing that we have to consider is the notion of incorporation, that is, joining with other groups which have similar problems. We have to think on three levels of concern. First is the level of the acute stage of illness where respiratory problems could be life threatening and where technology and knowledge of respiratory therapy are important. Second is the rehabilitation stage. Finally, and most essentially, what happens afterward to make life worth living for those with respiratory deficits.

These are the areas that we have to concentrate on. If we, as polio survivors, are going to be effective, we have to join with other groups. We need to emphasize our unique concerns, but also join with others in fostering the quality-of-life issues that are so important and which we pioneered.

Reflecting on my own situation, that is really what happened to me. I felt that I had a big advantage because I was in a seminary. When I went back, I was treated just as another student. I had to pull my weight in the classroom and in other areas. I was made to feel like one of the boys, and that was a tremendous support. This sense of being part of the mainstream is extremely important.

Now, particularly with the awareness we have of aging in the polio victim, we have to concentrate on gaining knowledge about this phenomenon and developing the assistance that is needed.

Panel Summary: What factors led to a successful approach to meeting the needs of polio patients?

The Factors

1. A coordinated, mass media, public relations effort to raise public consciousness of the issues.
2. A multidisciplinary approach to funding with an emphasis on private voluntary sources for polio (National Foundation - March of Dimes) with input from disabled consumers. There was a designated funding source which also acted to create an international organizational network to share research findings.
3. Applied research drawn from a pooling of medical science and engineering technical resources.
4. The existence of specialized regional centers for optimal, psychological, physical, and social support. Regional centers also served as a documentation center for the dissemination of information, the education of professionals, and for conducting research. The leadership of the centers was outstanding and effective.
5. A massive public involvement: concern by both health-care providers and the community, fueled by fear and sympathy, in a very real crisis environment. There was a defined crisis, and it concerned children.
6. A major health-care issue: for the first time in history, a very large group of survivors of intensive care lived, and the community had to do something about them. Some survivors, including President Roosevelt, became important public role models.
7. The community responded to survivors with coordinated resources that provided for independent living after hospitalization. The efforts included volunteering, private and public sector funding, and incentives for independence.
8. Polio survivors created a unique public perception of the disabled. The attitude of polio survivors was positive. They did not act sick; they wanted to go home -- on portable machines -- to live independently.

Panel Recommendations

1. Reeducate the public. The fear is gone, and the awareness is gone, except here at our meeting.
2. Create a national organization. A new approach is needed, similar to the National Foundation. The new organization should involve the disabled people who are aware of their own problems and needs.
3. Establish a nationwide communication center to disseminate information, reach out to private and public sector interests, educate the organizations and people needed for the welfare of the polio survivor (e.g., insurance companies, politicians). This registry of information can coordinate a network of consumers, professionals, and service organizations. For example, any person or organization can obtain information on the resources required (e.g., available equipment inventory, repair service, knowledgeable professionals).
4. Focus government funding on a project to study chronic respiratory insufficiency and the needed technological assistance.
5. Create a consortium of disabled people, including polio survivors and others with neuromuscular disabilities, to combine resources and create a collective strategy for public awareness and financial support.
6. Create and define a crisis that society in general will understand. Incorporate our current concerns within other similar concerns, so that we can present a larger and more urgent crisis. Join forces with other groups who have similar problems -- a result-oriented approach. We need a defined crisis which will generate an emotional response.

SESSION II

**THE PRESENT: A CRISIS? THE NEED TO DEVELOP
COST-EFFECTIVE AND PERSONAL SERVICES FOR POLIO SURVIVORS**

OPENING REMARKS

Ernest W. Johnson, M.D., Moderator

Professor and Chairman, Department of Physical Medicine,
Ohio State University Hospitals, Columbus, Ohio

This afternoon we are going to talk about what is happening now. The question is, "How can we manage the need to develop cost-effective and personal services for polio survivors?" I would like to add three more adjectives to "cost-effective" and "personal"; they are "appropriate," "efficient," and "meaningful."

I will never forget the group of architects I was meeting with to determine how many accessible toilets were needed in a six-story building. Their conclusion was that they needed to put only one on

the third floor, in the middle. I suggested that the person who was impaired or disabled might need a more appropriate solution.

For a perspective on what is happening now, I would like to introduce the viewpoint of a health-care professional, Alice Nolan. Ms. Nolan has just completed and is currently analyzing a research program funded by the Rehabilitation Services Administration (RSA) on the respirator-dependent individual in the New York City community.

HEALTH-CARE PERSPECTIVE

Alice Nolan, R.N.

Research Associate
Goldwater Memorial Hospital, New York, New York

A study was undertaken to determine cost-effective, personal service for post-polio survivors and others requiring respiratory support. Eighty-six former patients at Goldwater Memorial Hospital were interviewed, all of whom now live independently in the community in a variety of life styles, despite their requiring technical support for breathing. The adaptive potential of human beings is something we can all learn from. The goal of community integration presents new challenges to health-care professionals as well as their clients. The development of new, community-based services will greatly depend on the education, awareness, and attitudes of the practicing health-care specialist.

* * * * *

A Need Study to Determine Cost-Effective, Personal Services for Post-Polio Survivors and Others who Require Respiratory Support

I was invited to speak to you about the need to develop cost-effective and personal services for polio survivors. During the past few years I have been working with Drs. Howard Rusk and Mathew Lee, under a grant to study the independent living expenses of persons who are severely disabled. Our intention was to explore the needs and alternative living concepts of severely disabled persons. It has been a real learning experience for me and a consciousness-raising one in many ways.

Our survey was directed to people with a wide variety of needs. My own study focused on multiple clients in general; the people I visited had a range of disabilities and varying degrees of immobility. About half of the population was composed of people who had had polio. All those I surveyed had in common the need for respiratory support in order to live with their respective conditions.

The Crisis - The Need to Develop Services

When we speak of the crisis in medical care, we tend to associate it with the need for acute care, with patients, and with sick rolls. These labels are learned by the able-bodied professionals; we hope that in the future such terms will be discarded by public officials and professional educators. There is an urgent need for accessible, long-term, community-based services suited to the handicapped client.

From our discussions this morning, it is obvious that successful acute care, followed by appropriate rehabilitation intervention efforts, has increased the longevity of individuals with neuromuscular disease. The augmented potential for integrated activity and expanded life styles correlates with improved and consistent medical management, education, and applied therapy. More importantly, however, we need to publicize that being immobile with respiratory insufficiency does not mean that the person is a perpetual patient.

The Early Analysis of our Study - Introduction

I would like to share with you some of the findings of our study and raise some interest in discussion. Instead of reading statistics or criteria of significance, I prefer to talk to you about the people. [The data presented are included in the text of the proceedings in a table format for ease of study. Contact Dr. Mathew Lee, Director, Department of Rehabilitation Medicine, Goldwater Memorial Hospital, for a copy of the final study. -- Ed.] The people are doing surprisingly well. I visited 86 people in real-life situations and realized there is no single definition of independent living or sole solution to an independent life style. The conceptual styles and strategies developed by the clients help professionals realize the rich potential of human beings to adapt. What we must ask ourselves is, "What would we do in the same situation?"

The Population

Our population included people disabled by polio, muscular dystrophy, spinal cord injury, transverse myelitis, cerebral palsy, and multiple sclerosis. Most of the people either had muscular dystrophy or polio. With the exception of two volunteers, all of the people had received respiratory support and rehabilitation at Goldwater Memorial Hospital. Even after relocating to new neighborhoods, many of those interviewed returned to Goldwater for yearly physical examination and pulmonary function testing.

The Method

My visits lasted from two to eight hours. We discussed the frustrations and satisfactions of community living. The interview schedules had ten sections, amounting to 36 pages in all.

There are many data that we can speak about. We are completing the last phase of statistical analysis, but I can share some preliminary findings with you.

Table 1

| Sex | |
|--------|-----------|
| Male | 46 |
| Female | 40 |
| | <u>86</u> |

Table 2

| Age | |
|-----------|-----|
| 20+ years | 95% |
| 30+ years | 75% |

Table 3

| Gainful employment - 20% of total | |
|-----------------------------------|-----|
| Professional/managerial | 43% |
| White collar | 25% |
| Studying | 13% |
| Sponsored by programs | 7% |
| Other -- volunteers | 12% |

Table 4

| Education | |
|---------------------|-----|
| High school diploma | 25% |
| College course | 31% |
| College degree | 18% |
| Masters degree | 11% |
| Postgraduate course | 3% |
| Ph.D. | 1% |

Table 5

| Social living arrangements | |
|-------------------------------------|-----|
| Live alone | 43% |
| (alone 22%) (with attendant 16%) | |
| Married | 22% |
| Children | 6% |
| Live with families | 11% |
| Live with siblings | 11% |

Table 7

| Health status (self-rated) | |
|----------------------------|-----|
| Very good health | 15% |
| Good | 32% |
| Fair, poor | 14% |

Table 9

| Other respiratory support | |
|---|-----|
| Tracheostomy | 10% |
| 10 minutes "free time"* | 18% |
| Breathing exercise | 16% |
| Medical supervision with exercise required | 9% |

* "Free time" is the time of spontaneous breathing (or glossopharyngeal frog breathing) during which no mechanical aid is required. This was a factor in speaking with people as the average interview lasted from two to eight hours. People took time, but they were really cooperative.

In general, people arrange their support time according to their life styles, and they know when to use support. When they feel as if they are getting a headache, they use their machines. The severity of respiratory insufficiency -- indicated by the support required -- says a lot about what people can do in spite of a restrictive lung disease. People can get up and go out on a respirator. It is up to us to inform the community about their potential.

Table 6

| Functional ability | |
|--|-----|
| No hand function | 20% |
| One hand | 20% |
| Only finger motion | 5% |
| Hand function with upper arm weakness | 50% |

Table 8

| Pulmonary function | |
|--------------------|-----|
| 0-10% VC | 15% |
| 10-20% VC | 18% |
| 20-30% VC | 16% |
| 30-40% VC | 11% |
| 40-50% VC | 10% |

Impressions from the Results and Recommendations

The problems of the respiratory client can be better understood by distinguishing between health maintenance and a full-time sick role. Services must change as the patient's perspective changes from that of a former patient to a person in the community.

Accessibility - Transportation. The former residents of Goldwater Memorial Hospital are at present doing very well. What they need now is more consideration as members of the community and integration into available health services with accessibility as well as transportation to medical facilities. People who have funding from SSI or Medicare can arrange for their transportation. Some people have vans; others depend upon what they

can arrange with volunteers. People return to Goldwater because of its architectural access. Unfortunately, there are no other facilities with easy access for the disabled which also have expertise in pulmonary function testing.

Education - Attitudes. We must develop the goal of educating doctors and nurses to the special needs and talents of our clients. Nursing education today does not really prepare the nurse to attend to respiratory or immobile clients. Equally, we must raise the consciousness of doctors -- gynecologists, cardiologists, dermatologists, internists -- so they will choose office space accessible to disabled people so that they may have a choice in where they go for services.

Personal Economics. The economic attitudes of health professionals also play a role in providing needed services. Will professionals accept third-party payment as reimbursement for their services? Only 10% of our population have private medical coverage; only 6% pay for themselves.

Client Education. In regard to client education, persons who had polio in the past know more about their bodies than anyone else. The situation is otherwise for newly disabled people, those with muscular dystrophy, spinal cord injury, etc., who need to learn about their bodies and their equipment so they can teach health professionals who might not know a great deal about their condition.

Personal Assistance and Advocacy. Documentation is another area where trained people are needed to complete the

forms and act as advocates for clients who cannot act in their own behalf.

One of the extra and valuable roles Dr. Alba has played over the years is that of advocate. When a person has run into problems with Medicare payments for equipment, supplies, or attendant care, she has come forward. She has also helped a lot of other people do the same. Advocacy of this kind is not readily available, but we professionals need to act as advocates. We need to know that just because someone has a restrictive lung disease it does not necessarily mean that he cannot function as a person.

Acknowledgments

I learned quite a bit during this study, thanks to individuals such as Marilyn Saviola. Marilyn is a respiratory-polio survivor who formerly lived at Goldwater. She now lives independently and works at Goldwater as a Rehabilitation Counselor. Traveling with her by air across the country and on Amtrak to Washington definitely was a learning experience for me.

I would also like to thank some of the nurses with whom I have worked, because nurses are so rarely given credit for the fine work that they do. Dolores Sitbaum, R.N. has been doing rehabilitation nursing since 1956. She was at Goldwater's original polio center and now runs the Spinal Cord Injury Clinic at Elmhurst Hospital. Ann Johnson, R.N. is another. She worked at the Goldwater Respiratory Center and is here as personal attendant and friend of Marilyn Saviola.

REACTOR: HEALTH-CARE DELIVERY PERSPECTIVE

Ann A. Bailey, M.D.

Staff Physician,
Roosevelt-Warm Springs Institute for Rehabilitation,
Warm Springs, Georgia

A definite medical crisis for polio survivors has been observed at the Warm Springs Institute. Polio survivors have been reporting increased weakness, often in extremities considered unaffected by the polio, and an increased need for assistive devices. The symptoms include chronic fatigue and unique pain. The cause is unknown.

The crisis includes such factors as the decreased functional ability of the polio survivor, the unfamiliarity of the medical community with polio and older surgical techniques developed for the long-term stabilization, and the lack of individualized equipment or services.

Research is recommended to understand the phenomena, rediscover applicable old techniques, and apply new technology.

* * * * *

Miss Nolan established that we have definite needs for cost-effective, appropriate, efficient, meaningful, and personal services for chronic, ongoing problems. She especially drew attention to the social problems that people with disabilities are having.

A Crisis - New Medical Issue Concerning Polio Survivors

I would like to emphasize the medical problems that we have noticed lately. I want to give particular attention to the question mark after the word "crisis" in

the topic heading for this session.

At the Warm Springs Institute we have become very aware that a lot of former polio patients are having problems they did not previously have, and we do not know why. It may just be aging. It may be that the muscles they have used through the years have become compromised and are unable to perform any more. Whatever the reason, polio survivors are having more problems than they did.

We have been impressed with many of them coming to us saying, "It is not my leg that I have had braces on; it is my good leg." "It is not my weak arm; it is my good arm that is giving me trouble now." We do not know whether it is because that extremity has had to bear the burden of activity over the years or whether it has something to do with the polio itself.

Many people who have been independent and ambulatory are finding that they need braces. Some are even having to resort to wheelchairs. Most complain of chronic fatigue, and quite a number say they have pain. They try to differentiate this pain from the type of pain engendered by a knee that is over-stressed and in which arthritis has developed. They say it is not that kind of pain; it is different.

The Elements of the Crisis

We believe that there is something

going on in these people other than just the stress of joints and muscles, but we do not know what it is or the reason for it. This, I think, leads us to a definite crisis at the present time. These people have been quite functional for many years, most of them for 25 to 30 years. They have refused to be disabled. That polio survivors are now seeking help makes us believe that there is a medical crisis.

I have to say polio patients have brought it on themselves, because they are so independent and so determined not to be disabled. Most of them have had little contact with other people who have had polio. They have integrated themselves into society. They have not wanted to be considered different or looked upon with any special thought in any way. As a result, the public has let them go ahead.

People who had polio did not go to the doctor unless they had something terribly wrong with them. They got along all right with their muscles and did not have periodic health checks. Many of the

earlier surgical techniques were developed, not for the acute stage but for stabilization, when the extent of disability was established. Now these techniques have been forgotten. The result is that doctors are no longer familiar with polio.

In addition, the need for individualized equipment has not been widely recognized. People who have had polio -- and disabled people in general -- cannot manage with off-the-shelf equipment. They need individualized braces, corsets, crutches, whatever, and that service is not readily available any more.

Recommendations

I strongly believe that these developments lead us to the need for definite research. We need to find out what is going on, to rediscover some of the old techniques, and develop an organizational approach for putting into service some of the newer technology.

CONSUMER PERSPECTIVE

Margaret C. Pfrommer

Consumer Advocate and Research Associate,
Northwestern University Rehabilitation Engineering Program,
Department of Orthopaedics,
Northwestern University Medical School, Chicago, Illinois

President, Illinois Congress of Organizations
of the Physically Handicapped, Chicago, Illinois

Contracted polio in 1956, is quadriplegic,
and requires respiratory assistance

Five areas of concern are illustrated by five actual situations. The situations are analyzed and actions are proposed.

1. There is a lack of knowledge about respiratory insufficiency and post-polio survivors' medical needs:
Create educational awareness programs for doctors, allied health personnel, and consumers.
2. There is a lack of awareness of the availability of existing resources and their locations:
Create a documentation registry center to identify and coordinate available resources for interested consumers, professionals, and organizations.
3. There is a lack of positive concern for the health situation and a lack of understanding of alternative life styles, feelings, and values of post-polio survivors and others with severe disability:
Create public awareness among the general population and the medical community of the value of people with disabilities.
4. There is disregard of the fact that chronically disabled people are "tuned-in" to their own bodies.

Health-care professionals do not believe that consumers can play a significant role in their own health care:

Create mechanisms for consumer input into health-care delivery, such as in-service education, consumer involvement on boards of directors of health-care facilities, and consumer advocacy organizations.

5. There is a lack of medical information about the differences between acute crises in polio survivors and chronic needs for care. Indecision leads to high medical costs:
Establish special funding sources for chronic disability hospitalization and alternative lower-cost health-care delivery mechanisms for the disabled population.

* * * * *

Reaction to Dr. Bailey

I want to comment briefly on what Dr. Bailey said. First, I believe I have all the symptoms you mentioned. Second, I think modern technology can be more helpful than it currently is to people who have had polio. With the improved design of technical aids there could be a more

general application and less need for full-customizing.

Five Concerns

I plan to present five areas of concern to people with disabilities and deal with each concern in three parts: the situation, the analysis, and an action proposal.

Situation: Over the years I have had experiences in which medical personnel wanted to obtain or replace respiratory equipment that I have used for a long time. They seemed to have no understanding of or sensitivity to my dependency on this equipment and my confidence in being able to work with it successfully. I formerly thought that such experiences were mine alone, until I began to live a less-isolated life, and ultimately became an advocate for others.

One woman I came to know who had had polio was being seen as a client in a rehabilitation engineering clinic. (I use the term "client" because the clinic was not providing medical care or treatment.) She was there to take advantage of modern technical aids which could help make her life easier and obtain advice and information on how to keep her power units operating in the event of an electrical failure in her home.

During her clinic visits, a respiratory therapist was asked to sit in so that she might contribute her expertise with regard to respiratory equipment. She seemed impatient about the equipment that the client was using and, specifically, could not understand the Eureka blower. She made such statements as, "I don't know why it was originally prescribed. I don't know how the amount of air is regulated, and I don't understand how it is different from the equipment we use now." The therapist's response was, in effect, to insist that the client give up what she knew and trust in what the therapist understood. For the client, it

was a threatening situation and not conducive to making her comfortable with the prospect of change.

I am sure that the therapist was correct in asking the client to use more modern equipment. It is easier to obtain and maintain, and trained personnel exist who know how to apply it. The problem was that at no time did the therapist express her willingness to learn about the old equipment and what it had been doing. The client was then hesitant to rely on a teacher who made it obvious that she did not know her subject.

Analysis: From this experience, I came to the realization that both the client and the therapist needed further educating. There is a widespread lack of knowledge and awareness concerning respiratory insufficiency and the post-polio survivor's medical needs.

Action proposed: My choice of action would be to create educational awareness programs for respiratory therapists, nurses, doctors, consumers, and others about chronic respiratory insufficiency. Such programs could be offered in connection with association meetings and educational conferences.

Situation: My second area of concern is rooted in an experience that occurred some years ago when I entered the hospital as a post-polio patient with double pneumonia. None of the medical staff responded as knowledgeable people. By chance, during the next three days, I was visited by old friends who were nurses. It had been many years since I had seen any of them.

Each provided some help. One located and produced a piece of respiratory equipment that I would ordinarily be using. It was a rocking bed. The second encouraged me to try a piece of equipment new to me, and she confidently taught me how to use it. It was an intermittent positive pressure ventilator. This kept me alive until the third visiting

nurse arrived, just in time to show the staff how to place me in an iron lung. The iron lung was the respiratory aid I had requested at the time of my arrival at the hospital.

Two of these nurses did not even work in the hospital where I was staying. They worked in hospitals nearby, however, and could have been used in a formal way as a resource for polio-related problems. Although I did not die of respiratory insufficiency, the incompetence of the hospital staff almost scared me to death.

Analysis: It is evident that, although those assigned to my care were poorly equipped, there were in the medical community those who could have been formally called upon. This points to a general lack of awareness of the availability of diverse resources and their location.

Action proposed: Create a documentation registry center to identify and coordinate available resources for consumers, doctors, and anyone else who is interested.

Situation: A third area of concern relates to occasions when I have been hospitalized and overheard comments by medical personnel about my helplessness and the futility of my life. What they indicated was a general belief that it would be better for all concerned if I were dead. It is a hard thing to hear. I have also overheard similar statements about disabled friends of mine when they were hospitalized.

Recently, I visited such a friend who was very ill and looked very helpless. I considered it necessary to alert two members of the medical staff that this person was beloved by many and important to the lives of many hundreds of others because of his advocacy. Such admonition should be unnecessary, but I definitely felt a reluctance on the part of those two professionals to use every available resource in his behalf. I needed to tell them what kind of person he was so they would get a

different picture in their minds.

Analysis: From this experience I concluded that there is sometimes a negative attitude about the health situations of people who are post-polio survivors and others with disabilities. Medical personnel often lack a positive concern for the right to life of all the hospitalized and lack understanding of alternative life styles, feelings, and values.

Action proposed: Generate widespread public awareness, especially among medical personnel, of the value of life to people with disabilities.

Situation: A fourth area of concern is the frequently heard complaint of many who have had polio and other disabilities that they are not listened to when receiving medical care or treatment. For instance, a lab technician ignored my admonition that he would not be able to draw blood except from one particular location. Therefore, I was subjected to needle penetration more than two dozen times in various parts of my body before he asked me where the blood had been drawn previously. This kind of behavior is exhibited by some x-ray technicians, nurses, therapists, and doctors.

When I go into the hospital now, much older and wiser, I say two things. I tell them the place where they can draw blood, and I give them two chances to stick me. If they fail to listen and use up their chances I insist that they "come back tomorrow." I have learned to be more my own advocate.

Analysis: From my experience, I have concluded that the reason for this mistreatment must be that members of the staff are handling the situation in their routine fashion, disregarding the fact that people who are chronically disabled have been tuned in to their bodies, know what works, and know what can aggravate their particular condition.

Medical support personnel do not believe that consumers can play a signifi-

cant role in their own health care. Because of this, the medical personnel create further physical and emotional stress during delivery of "care," and I put the word in quotations because, obviously, it is not care.

Action proposed: Establish mechanisms for consumer input into health-care delivery, such as in-service education and inclusion of consumers on the boards of directors of health-care facilities. I also urge utilizing or setting up mechanisms for input from existing consumer advocacy organizations.

Situation: The fifth area of concern manifests itself in the experience of a friend who had had polio about 40 years previously and went into a hospital for a problem unrelated to his disability. After a few days in the hospital, he had a pulmonary arrest and ended up in an intensive care unit, one of the best in the country. The staff was not familiar with his disability, and I got the impression for a while that they did not know what direction to go. He himself had not had any experience as a respiratory patient since he was a child and therefore did not know what his alternatives might be. Al-

though the staff did an excellent job of keeping him alive, his expenses in the ICU and other units in the hospital were extremely high.

Analysis: There are two problems here. One is that people seem to be going into pulmonary arrest very suddenly. The other one is the high cost of this kind of care.

From my friend's experience, I concluded that indecisiveness and lack of information add greatly to hospital costs. My friend is an insurance broker and had a good policy. Nevertheless, the cost to him personally was still high. I am fearful that those people without policies, those who must rely on the government, may not have future continued support. Will those people who do not have the means to pay lose care? Will they receive less care than those who can pay?

Action proposed: I propose to initiate a dialogue with public and private agencies to keep them tuned in to the needs of this particular disability group. Create special insurance or hospital plans for them. Also, we can develop better systems of health care for the disabled population so as to keep the costs as low as possible.

REACTOR: CONSUMER PERSPECTIVE

August W. Christmann

Executive Director, Illinois Congress of
Organizations of Physically Handicapped, Chicago, Illinois

Insurance broker,
Contracted polio as a teenager in 1940

The crisis confronting the post-polio survivor is defined in terms of the following needs:

- . To educate medical personnel
- . To increase consumer advocacy
- . To develop awareness about post-polio aging consequences
- . To improve health-care personnel and consumer relationships
- . To apply existing technological resources

* * * * *

A Personal Experience - A Need to Educate Medical Personnel

A number of years ago, I had the misfortune of having a gallbladder that was acting up. My internist recommended surgery. We promptly went to the hospital and proceeded with the preoperative procedures. I kept saying, "Don't forget that I was a bulbar polio. My lungs were involved." The response was, "Oh, yes, we know, we know."

The night before the operation, a nurse anesthetist proceeded to tell me what was going to happen the next day. I reiterated, "I am post-polio. Don't forget my lungs are involved." "Oh, yes, yes. We know that," she assured me.

The gallbladder surgery went ahead, then something happened on the table. I almost died. They rushed me to intensive care, and I was there for eight days as a result of what should have been a routine

gallbladder operation. It turned out they had done something that interfered with my diaphragm. They did not know, and I did not know.

Six months later, I went into the same institution for a kidney stone. Well, I can tell you I got different attention that second time. The anesthesiologist (M.D.) -- the expensive one -- came to visit me the evening before the operation. He assured me that he would be there through the whole procedure and that they would be meticulously careful about my ancillary problem. Well, they were, and I was in intensive care overnight. What this experience shows is that, maybe, the medical profession can learn, if we scare them enough!

A Need for Advocacy

I want to make reference to a comment made this morning about the broader problems of the disabled in housing, transportation, and so forth. Margaret Pfrommer is president of a consumer advocacy organization that spends all its time in efforts like this, in improving the life style, housing, education, rehabilitation, and so forth, for all the disabled in Illinois.

In Illinois, it is happening. You can judge how successfully. It is a matter of degree, but we do have advocacy in this state.

A Need for Awareness about Post-Polio Aging Consequences

Many polio survivors are not aware of the effect polio has had on their present condition. I associate with a good number of people who are post-polio survivors and who have had no respiratory involvement. They are living full, active lives with families and are not having problems with such things as arthritis and bursitis. You can imagine the problem posed by a man who puts his full weight on crutches and then develops bursitis. The doctors really do not know how to treat him because there is no way to rest that shoulder unless he is going to become incapacitated. If he becomes incapacitated, he becomes unemployed, and if he becomes unemployed, his family is going to suffer. So, he works, and he will continue to use that shoulder and abuse it. These are some of the problems that exist.

A Need to Improve Health-Care Personnel - Consumer Relationships

In regard to the doctor-patient relationship, all I can say is that we still have a long, long way to go. I think a conference like this is a magnificent first step.

A Need to Apply Existing Technological Resources

In regard to the application of existing technology, I think we could possibly use, as an example, the solution found by people with kidney failure. They have available dialysis stations and home portable systems that are funded by the federal government, but I don't know how effective or costly this idea would be. Possibly we could piggyback onto that kind of system for respiratory insufficiency.

ORGANIZATIONAL PERSPECTIVE

James C. Campbell

President, LIFECARE Services, Inc., Boulder, Colorado

LIFECARE is a service organization that provides post-polio survivors and others who have long-term respiratory insufficiency with mechanical aids for breathing and the service these aids require. The organization responded to a need for this type of service in the 1960s and has grown to meet the new needs of thousands of people in the 1970s and 1980s. Three challenges facing the organization at present are (1) gaining an understanding of why one ventilator is not enough; (2) licensing respiratory therapists; and (3) determining the value of rental vs. purchase of major equipment.

* * * * *

Introduction

I am going to make some introductory remarks about what our company is doing and why we believe we have reason to be contributing to this program. Then I will define some terms which we use in our business and explain how they apply to my further remarks. Lastly, I will review the three major challenges which we are dealing with in our company today.

How our Delivery System Grew to Meet the Present-Day Need

LIFECARE began business about 13 years ago. There was no private organization at that time dealing with the needs of people using respirators at home. We thought there was a need for this kind of service, and we started LIFECARE.

Initially, we looked to the March of Dimes which, in our opinion, had very

successfully dealt with this challenge during the epidemic years of polio. In those years, as many of you know, there were across the United States as many as 22 respiratory centers dealing with post-polio survivors who had gone home with iron lungs, chest cuirasses, and other types of respirators. We wanted to have a similar organization. We knew that we needed professional, experienced technicians able to deal with the various equipment problems associated with home respirators.

We took advantage of the example of the March of Dimes and began our trip around the country seeking technicians who had worked in the March of Dimes polio centers during the epidemic years. They were Larry Rambo (St. Paul), John Hernandez (Houston), Don Seeley (Cleveland), Jimmy Mercer (New York), Carlton Bishop (Augusta), Tom Aaron (Ann Arbor), Harry Larson (Grand Rapids), Warren Wohlgemuth (Detroit), Ted Cranton (Boston), Steve Simpkins (Baltimore), Otto Prokop (Omaha), and Gene Provinse (Los Angeles). We attempted to hire these people and, in some instances, we succeeded. We were fortunate to have these experienced people and others join LIFECARE from 1968 to 1970 during the formation of our nationwide home respiratory service.

Since polio individuals made up the majority of those at home with respirators in the late 1960s, we were primarily in the polio home respiratory business. That is how LIFECARE began. Today, there are thousands of people at home in America with all kinds of respiratory conditions who are using respirators. There

are approximately 800 to 1,000 polio individuals at home today with respirators. There are perhaps, four or five times that number at home today with respirators for other conditions.

The Success of our Delivery System

We believe that the present delivery system -- the job of taking care of these respirators and the individuals who use them -- is succeeding. It is a complicated system, but perhaps meetings like this can help to simplify the delivery system. Evidence of the success of the service is that so many people are able to attend sessions like this, using respirators, and are also able to lead a regular, useful, contributing life.

Our Definitions

Before identifying the challenges we face at present, I would like to clarify some of the terms we use. We use the term "clients." We consider clients to be people, individuals, who have gone home with respirators. "Patients" are people in hospitals who use respirators, and we believe a patient becomes a client when he goes home with a respirator.

There are respirators and ventilators. These words in our business are often used interchangeably, but there is a difference. A "respirator" is a pressure-cycled device; a "ventilator" is a volume-controlled device. Ventilators are of a more recent design and technology; respirators are from an earlier design vintage.

We refer to "professionals" as a broad group, one that includes doctors, respiratory therapists, nurses, physical therapists, occupational therapists, etc. These professional people make the medical decisions that influence our business.

LIFECARE is considered by insurance companies and medical agencies to be a "D.M.E." supplier, which stands for durable medical equipment. D.M.E.

suppliers are manufacturers and dealers providing, manufacturing, and servicing respirators and support equipment for individuals at home.

"Financial agencies" are organizations that pay the bills and are actively participating and sharing in the financial burden of funding these programs. The largest tax-supported groups are Medicare, Medicaid, the Veterans Administration, crippled children's organizations, vocational rehabilitation organizations, and the supplement Social Security programs. The largest private agencies and organizations are the National Foundation - March of Dimes, Muscular Dystrophy Association, insurance companies, and labor unions. All of these groups, private and tax-supported, share in paying the bill for respirators at home.

The Challenges that Face Us

One challenge from financial agencies regards the number of respirators that should be allowed in a home. Many of these agencies believe that one respirator is enough. I know from the group I am speaking to here that many would be horrified to think of living day-to-day with a single respirator. [The home ventilation programs developed at Children's Memorial Hospital in Chicago endorse a policy of more than one ventilator -- for safety and mobility. Other programs, e.g., Goldwater Memorial Hospital in New York, concur with this recommendation. -- Ed.] LIFECARE believes there is an educational task ahead in helping these organizations and agencies understand why one respirator is inadequate. We acknowledge and agree with the desire of these agencies to conserve funds. However, the experience of the original polio home respirator clients proved that one respirator is insufficient. We doubt if you could find a polio client with but one respirator at home.

We know from experience that different types of respirators are needed for different situations during the day.

[Mechanical aids for breathing, i.e., respirators and other support devices, are medically prescribed to meet each individual's daily living situation. -- Ed.] Frequently, the nighttime respirator is of a different type from the daytime respirator. Perhaps a rocking bed or iron lung serves as the nighttime respirator and a smaller, portable respirator is better suited for daytime use. The portable respirator may be used with a wheelchair or in an automobile, in school or at work.

Today's rehabilitated respirator client is on the road. This is good! We are impressed with the independence achieved. These clients need not be bedridden. A single respirator confines them to a bed. We believe several respirators allow the client to be mobile.

There is excellent portable equipment available today. I hope most of us here know this. Our experience has proven that continually to be taking down and setting up a portable respirator is not a practical daily procedure. Routinely changing the setup is necessarily going to increase the frequency of equipment service and maintenance. Consequently, we believe that a minimum of two respirators is reasonable for a client at home.

Another aspect of the single respirator challenge is emergency service. Those who believe that a single respirator is adequate believe that it can be backed up and supported with emergency service. We do not agree. A respirator failing at 2:00 a.m. is going to cause severe problems, no matter how good the emergency service and support is. We believe it is better for a client to be able to make a change in equipment, go back to sleep, and deal with the service problem in the morning.

We believe it is important for a client to go home with a respirator and feel secure. If he can have two or more respirators at home to be set up and used routinely, there is a good, secure feeling in knowing that alternate equipment is at hand for emergency use.

Our second challenge is the licensing of respiratory therapists. I am hoping that most of you know who respiratory therapists are. They are an important group of trained, educated respiratory technicians. They commonly operate in hospitals in conjunction with physicians and others in the hospital organization. However, they lack the necessary license status for home visits. This means that they cannot be reimbursed for their services when they go into a respirator-dependent client's home.

As a consequence, this needed service is being provided by D.M.E. suppliers who employ respiratory therapists. Unfortunately, we believe this arrangement poses a significant conflict of interest for respiratory therapists. We would like these therapists to become licensed so they would have the same status as a physical therapist and an R.N.

We believe that, in time, respiratory therapy home service will become routine. LIFECARE employs respiratory therapists today, and their numbers are growing among D.M.E. suppliers. We are beginning to use them on routine visits to evaluate clients in the home. The therapist then sends a report to the client's physician to help determine the success of the home use of the respirator. [The practice, as described, has been in operation in London, Paris (ADEP), and Lyon (ALLP) for 15 to 20 years. The costs in Europe are drastically lower than those in the United States. -- Ed.]

Our third challenge has to do with rental versus purchase of respirators. We are pleased that great progress has been made in convincing agencies to select a rental rather than a purchase agreement for providing respirators and the important services that go with them.

Rental rates for respirators may be as low as 1% of the purchase price. For similar equipment, i.e., nonrespiratory, medical equipment, available in this country today, the rental rates are typically 10% to 15% of the purchase

price. Maintenance and service, which are so important for home respirators, are included in the cost of rental. On the other hand, to purchase a home package of respirator equipment costs from \$8,000 to \$10,000, exclusive of service and maintenance costs. When added to the other expenses required for a client to return home, it gets to be a very large sum.

Respirators, of course, do not last forever. The expected life of a respirator is about two to seven years. We can count on an expected average life of five years.

Post-polio clients, typically, have been rehabilitated and stabilized to live long, healthy lives. They will require and use respirators for life and will outlive their respirators by many years. If you purchase a respirator, you must consider replacing it with newer models as the years go by. A renter simply substitutes the new equipment as needed. Clients' needs change, and the equipment changes. There are some significant, exciting respirators available today. If someone had spent \$8,000 to \$10,000 a year ago on respirator equipment, he would probably be very disappointed today, for he would have to wait until his original investment had been absorbed before buying the new, more desirable equipment.

Summary

We are proud to be in this business and to know there is good home respirator service available. There is also a good selection of equipment available, such as iron lungs and rocking beds, as well as modern portable ventilators.

Service in most big cities is good; in more remote areas, it is adequate or satisfactory. Servicing remote areas is obviously more difficult, but equipment is available nationwide.

Discussion - Dr. Johnson

I have a problem with Mr. Campbell's definitions. Respiration is a function of the body, one of taking air in that goes all the way to the cells. So, the proper term is ventilator, irrespective of whether it is pressure or volume. Use the word ventilator for everything, and disregard respirator. And let us use patient, not client, because we do not want to be a client state.

I might also say that instead of getting worried about how long we are going to live and so on, let's face the reality that just being alive is a chronic and ultimately fatal disease.

REACTOR: ORGANIZATIONAL PERSPECTIVE

André Dessertine

Magistrate, Creteil, France

Former President, World Veterans Association

President, ADEP (Association d'Entraide des Polios Handicapés)

Invited guest of the U.S. Congress, 1976

Recipient of the Legion of Honor for service
to the disabled community of France

Contracted polio, 1962, in Paris and is paraplegic

ADEP has a component, known as ADEP-Assistance, that provides home ventilation services for nearly 500 people in the greater Paris metropolitan area. The cost of the service is currently about \$160 per month. The history of this organization, which brings together the interests of the consumer, the medical community, the Social Security system, and the services of the Association, provides a model for future organizations wishing to develop cost-effective, personal services.

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[Mr. Dessertine apologized for speaking in French. His commentary was translated by Dr. Goldberg as follows. -- Ed.]

History of ADEP Assistance

ADEP is an organization originally created to help polio survivors leave the hospital and return home. To accomplish this for ventilator-dependent people, we organized a home ventilation program in 1969.

Initially we had 17 individuals re-

quiring the service. Within six months, we had served 170 people. We have now grown to serve nearly 500 people who live in and around Paris.

Why Did It Grow with Success?

Essential to the success of the service was a reimbursement mechanism since most people did not have adequate financial means to pay the entire cost. The funding method we developed routed monies directly from Social Security to ADEP.

How Did We Determine What Services to Provide?

To determine what services we should provide, we persuaded Social Security to conduct a survey of needs. Then, before clients left the hospital, we determined criteria for home care. We asked people about their individual respiratory requirements, their particular needs, etc. This was done in the hospital because, there, all the necessary regulating and fine tuning of ventilators could be done with coordination by the medical staff. The equipment and techniques used

were many. We have available almost 50 different types of apparatus, including various types of ventilators and techniques, some utilizing mouth positive pressure breathing, some ventilating by tracheostomy. The individuals with tracheostomies usually had ventilation requirements of more than 15 hours per day.

What Services did ADEP Provide?

When a person had no independent breathing, we provided him with two ventilators. We provided equipment maintenance by special technicians who were familiar with the equipment and knew what to do if special problems arose with its use. This service developed into an

around-the-clock operation, with full coverage for holidays and weekends, and with emergencies answered within one hour of a call.

How Much did It Cost?

The cost of this service, always an important factor, has been reduced by our also providing equipment maintenance. For example, in 1970, the cost was the equivalent of \$100 per month. In 1980, the cost was equivalent to \$160 per month for the following services: the ventilator, immediate servicing, twice monthly maintenance of the ventilator, and regular visits by representatives from Social Security. ADEP now serves the entire Paris metropolitan area.

GROUP DISCUSSION

WHAT FACTORS TODAY MUST BE CONSIDERED TO MEET COMPLEX HEALTH-CARE NEEDS?

Joseph M. Kaufert, M.D., Ph.D.

Department of Social and Preventive Medicine
University of Manitoba, Winnipeg, Manitoba, Canada

Russell L. Beeson

LIFECARE Services, Inc., Pacheco, California
Contracted polio and requires respiratory assistance

A comprehensive need survey has been done in Manitoba. This model would serve other studies with similar objectives.

* * * * *

Dr. Joseph Kaufert

Introduction to the Manitoba Need Study

A number of groups have discussed the need to define the problem of health care by obtaining a more comprehensive profile of the needs of the whole population of polio survivors. In this regard, our experience in Manitoba may be relevant. A research study, carried out in 1980, attempted to trace everyone who had developed respiratory polio between 1950 and 1959 in the province. This research was funded by the Manitoba government and was conducted with the collaboration of Joan Bickford, Patricia Kaufert, and two physicians, Drs. John Alcock and John Hildes, who had been medically involved with polio patients during the 1952-1953 epidemics in Manitoba.

The Study Population

The study included a review of the medical records of 196 former patients

who had respiratory polio and had survived the initial onset of the disease. We traced over 80% of these people and were able to collect information by interview on approximately 75% of them. Because the study was based on a representative cross-section of people, it was a useful source of information. Although all the respondents had had respiratory polio, the residual impact ranged from minimal to severe respiratory involvement. Some were young children when they developed polio and were now in their early thirties; others had been young adults in the 1950s and now were approaching their sixties and seventies. A few had never left the hospital center to which they were first brought for care; others had been discharged after only a few months and never had to return.

The Importance of Appropriate Definition of Criteria to Determine Real Needs

The range of experience of the survivors included in the Manitoba study is pertinent to the problem of defining current needs. The objective of our Manitoba Respiratory Rehabilitation Conference was to look at the impact of aging, but the group of post-polio people who would attend this kind of meeting may not be typical. They were, for example, often

people who had remained in need of specialist care. In the Manitoba study, such individuals were a minority whose characteristics were distinctive and from whose experience it would be unwise to generalize.

One aspect of defining the current health crisis relates to the experience of people whose level of respiratory function has deteriorated with aging. Using our Manitoba data, we have looked at this question. During the interview, people were asked to assess their respiratory function as it was one year after they developed polio and as it is today. They were also asked what their worst and best level of function had been as measured by their dependence on respiratory equipment. The majority of the Manitoba respondents described a stable functional level which they had reached in the early years after developing polio and which they continued to maintain. There was an important minority (19) who said their condition had become worse, but they belonged to no special age group. Clearly, the impact of the aging process on respiratory function requires much further research.

Other Benefits from the Need Survey

One spin-off of a comprehensive follow-up study, such as the Manitoba one, was to put post-polio people into contact with their former networks of polio survivors and clinicians who can relate to their current problems. Although more than half of the Manitoba people had lost contact with the clinicians and were not active in the disabled consumers' movement, a high proportion participated in two follow-up meetings where they discussed their experience.

Future Directors for Need Assessment

The relationship between care needs and care resources was a major concern of members of the discussion groups. Never has it been a static relationship.

As people have grown older their needs have changed, whether as disabled children growing into adulthood or as young adults entering early and late middle age. At our first conference, the emphasis was primarily on the aging of the individual; in the next stage of the Manitoba study, we want to broaden this perspective and look at the aging process as it affects people in wider family settings and their ability to provide support. Established patterns of living may be threatened not only by changes in the individual who has had polio but by the aging of those on whom they depend, such as a parent or spouse.

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Russell L. Beeson

As a post-polio survivor, I would like to tell you or remind you that a lot of the ideas presented from an earlier era will not work today because, as post-polios, we are a different breed. The very nature of the illness was different from a lot of the illnesses we are dealing with today. Post-polios have guts. A lot of us would not be here today if we were not using our own resources.

You know, many of you, if you recall the days when you were in the hospital, you would have been dead if you had not told the doctor or the nurses that you needed help, right? So, it is going to be hard for us to relate our era to the present.

The equipment that was designed in the polio era had one alarm, and it sounded if the electricity went out. I deal with present-day equipment, and if I were to bring in a respirator like that, many of my customers would be horrified to learn that it does not have 25 alarms.

Well, think about that. Why did we live through that era? Because we had fortitude, guts, and that is what post-polios are all about. What characterizes our relationship here today is that we are all either post-polio survivors or work with it or know about it. We have lived with it a long time.

It would be nice if a lot of the actions proposed today would happen. I must quite frankly tell you that many things I am hearing now I heard ten years ago with the California Association of the Physically Handicapped when they were examining how to get the attitudinal and architectural barriers removed. It happened, but it took a lot of hard work, most of it done by the handicapped themselves. I guess it is going to be up to us again, we post-polios and lovers of post-polios, to get in there and get something done.

Finally, I would like to ask you post-polios, do you want to be called patients or clients? [The response was "persons."] I know that, but if you had your choice, who wants to be called a patient? [The response was "no, call us people."] I am talking about the words patient and client, because as a vendor, if I mention the word patient to my clients, they interrupt the conversation to remind me that they are no longer patients. They are home now. Medically, that is wrong, but the next time you are out talking to some people, call them patients and see

what happens.

Panel Summary: What factors today must be considered to meet complex health-care needs?

The Factors

1. It is important that the problem of meeting complex health needs be precisely defined and assessed. Any new, emerging issue has a fuzziness which requires clarification before effective solutions can be proposed. For example, post-polio respiratory needs must be distinguished from other forms of chronic lung disease. Needs must be defined qualitatively and quantitatively.
2. It is impossible for consumers, professionals, or service organizations to be aware of all the potential resources that exist.
3. Any major new venture requires a funding basis.
4. The communication of needs should focus on target groups that have authority to make decisions and include an effective use of the public media. The media can concentrate both on personal cases and convincing statistical data.

Panel Recommendations

1. Systematically collect and organize information about the health problems of aging post-polio survivors in such a way that is available to professionals, consumers, and service organizations all over the world. The registry must be accessible by a toll free "800 number" or home computer. A network of information will lead to coordinated services and the creation of services when resources are not available. This service can be ex-

tended to all disability issues.

2. Introduce educational programs concerned with polio and post-polio aging issues into medical schools and postgraduate training. Educational efforts should also extend to existing agencies and government departments for the purpose of preventing new polio cases and determining the needs of those who survived polio.
3. The consumer has a responsibility to seek entrance into existing rehabilitation facilities for proper assessment and management on an individual case basis. Additionally, the consumer must advocate for unmet health-care needs to generate new funds and facilities to meet those needs. The consumer must take a responsible role in increasing public awareness for the needed service program.
4. Utilize the nucleus of this conference, including the talents involved, to create a permanent organization to deal with the issues raised at the conference. The organization can be involved with the distribution of equipment, the provision of health-care services by coordination of existing resources, the dissemination of information, and the education of professionals, consumers, and service organizations. The consumer must play a major role in this effort.
5. Utilize the media to increase public awareness of the problem. It would be valuable to offer predictions about the number of able-bodied people who may become disabled. Note that disability issues have implication for various disorders (heart disease, stroke, etc.). Victims of complications of these conditions will require the same types of services as people who survived polio.
6. Once needs are qualified and quantified, create a network of existing professional organizations and community groups to help meet those needs.
7. Adapt existing programs to meet new needs. For example, local YMCAs and spas can adopt some programs, such as physical education and swimming, for the disabled. Spinal cord centers can expand their programs to include all quadriplegics, even those with respiratory insufficiency problems.
8. Encourage insurance companies to underwrite broader alternative care coverage.

SESSION III

**THE PRESENT: TECHNOLOGICAL ISSUES - ARE PAST TECHNIQUES
AND PRACTICES DEVELOPED DURING THE POLIO CRISIS
APPLICABLE TO MEET PRESENT NEEDS?**

OPENING REMARKS

John O'Connor, Moderator

Vice-President and General Counsel,
National Foundation - March of Dimes, White Plains, New York

The National Foundation - March of Dimes still serves the ventilator equipment needs of approximately 700 people who are post-polio survivors. Carlton Bishop of the Foundation serves most of the people east of the Mississippi, and Jim Campbell of LIFECARE, those west of the Mississippi. The services cost the Foundation about \$500,000 a year.

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Service and Cost of Ventilator Equipment Needs

For nearly 23 years, I have been the general counsel for the March of Dimes, and for the last 12 years have acted as overseer of the respirator equipment programs out of the national headquarters in White Plains. We still serve the respirator equipment needs of approximately 700

post-polio respirator users around the country. Carlton Bishop, from our Georgia pool, serves most of the people east of the Mississippi, and Jim Campbell's LIFECARE of Boulder serves most people west of the Mississippi. Service of ventilator equipment for 700 people costs about \$500,000 a year. The March of Dimes is happy to provide these services, and we intend to continue for as long as we are able.

Objectives of Session III

The general objectives of this session are to review existing and evolving technology that came into being because of the polio epidemics of the 1950s, and to determine whether or not these techniques and practices can be applied to present-day concerns.

HEALTH-CARE PERSPECTIVES

Augusta Alba, M.D.

Director, Howard A. Rusk Respiratory Rehabilitation Center

Associate Director, Goldwater Memorial Hospital

Associate Professor of Neurology and Rehabilitation Medicine,
New York University School of Medicine, New York, New York

The pros and cons regarding the use of various mechanical aids for breathing are discussed. These aids include the rocking bed, the iron lung, the chestpiece or cuirass, the poncho, mouth positive pressure, tracheostomy, glossopharyngeal or frog breathing, and the cofflator. Of these, the iron lung is still the workhorse of respiratory therapy, appropriate for anyone who does not have a tracheostomy tube during severe respiratory infection. However, it is bulky, it does not fit in a crowded ICU, and it is expensive to store. Medical staffs today lack training in the use of the iron lung and other ventilator equipment.

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The Rocking Bed

The rocking bed was my first introduction to the respirator rehabilitation wards. One day I came on the ward, and a patient who could still walk but not use his respiratory muscles, stopped his bed and stepped off it. This was a shock to me.

The rocking bed is still a useful means of breathing. The advantage is that it maintains body movement when it is otherwise impossible, and provides an augmented tidal volume by the up and down movement of the diaphragm. If patients suffer from any type of pneumonia or bronchitis, and breathing is too shallow on the rocking bed, then either an

iron lung or mouth positive pressure is needed. In recent years, however, many people without polio do not like to use a rocking bed.

The mattress frequently develops the shape of the individual, and many users of the rocking bed like having a hollow in the middle of the mattress to help them stay in one spot. Elevation of the head and feet also helps them stay stationary.

The Stryker gel foam cushion has been used by at least two of our patients. It is placed under the buttocks to help prevent sliding. There is a possibility, however, that the user may suffer friction burn or decubitus over the coccyx.

That most people will rock without safety straps is distressing to me, but they have started that way and do not want to change. Even in situations where people were without any degree of spasticity, restlessness, or agitation, ordinary bed rails were placed on a rocking bed for safety. Occasionally, we have convinced someone to use a safety strap.

There have been accidents with the rocking bed. One time a nurse unwittingly leaned against a nightstand, causing it to slip under the corner of a rocking bed that was in motion. The bed turned over. I saw at this particular conference that someone has designed a portable rocking bed which will stop when anything gets in the way. To me this is a good

addition to the bed. The beds we are presently using are not portable. It takes a team of workers and a few hours before a bed can be moved from a truck and set up in an appropriate room for use.

It is a wonderful bed for postural drainage, whether you have it at a 30-degree or 15-degree angle, head down. A woman with ALS has tried on two occasions to use a regular hospital bed, hoping that she would get enough angle to do postural drainage for her chronic bronchitis. She finds that the rocking bed better suits her needs.

I have not been able to convince people who are spinal cord-injured to use the rocking bed. It may be that the spasticity is somewhat exaggerated by the movement, since movement may trigger spasticity.

The Iron Lung

The iron lung is still the workhorse of respiratory therapy appropriate for anyone today who does not have a tracheostomy tube. This method of breathing is used during an acute respiratory infection. But when the mucus production becomes overwhelming, one has to switch to an endotracheal tube and ventilator and then be transferred to an ICU. Otherwise, an iron lung is sufficient for minor respiratory infections. A person will usually stay in a lung anywhere from one to three weeks, depending on the condition of his lungs. The iron lung is being used with good results in a number of our chest services for people with intrinsic lung disease.

The disadvantage of the iron lung is its bulk. I remember a time when a person, who had a bleeding duodenal ulcer and who used an iron lung, needed to be transported by a fire department truck from Goldwater to Bellevue. The sad thing today is that, although nurses may be willing to use the iron lung in an acute hospital setting, they have no training.

In a situation where a person is quadriplegic, critically ill, and apprehensive, the iron lung is the last choice of staff in an ICU. Most ICUs are too crowded and too small to handle the iron lung. The acute general hospital may have an iron lung in storage, but because it may be needed only once in every five years, it does not receive regular maintenance.

If anyone has a tracheostomy tube today, the treatment of choice is tracheostomy positive pressure ventilation. It is so much more convenient for a person to be in his own bed with the added comfort. If he is ill, it is easier to provide medical treatment and nursing care.

There is available in England the Kelleger iron lung, which can be completely turned like the Stryker frame, putting the occupant into a prone position for added postural drainage. The sections of the posterior lobes are not drained by any other technique except by lying on one's stomach. But it is very difficult to turn a quadriplegic person over on his stomach. Our center has never purchased a Kelleger iron lung simply because it is hard to justify the purchase of an additional lung when we have 15 standard ones in storage. Having enough space to store iron lungs when they are not in use is another problem.

Chestpiece or Cuirass

The chestpiece is still used by a number of people, and there are some good ones available on the market. The Monaghan chestpiece is still available, as well as chestpieces made by Thompson and LIFECARE. A problem that develops among long-term users of chestpieces is curvature of the spine. The chest wall will take on the shape of the chestpiece, usually called a turtle shell. With body growth, the amount of tidal volume one can obtain with a chestpiece, as the chest wall deforms, becomes less and less.

We have found that the majority of our patients who left the hospital went

into family care situations. Some have gained weight to the extent that their chestpieces no longer fit. Some have skin problems or have found that the mouth positive pressure breathing is a better technique, and so have abandoned the use of the chestpiece.

Earlier in this conference, Alice Nolan reported that only six people out of a total of 85 were using a chestpiece at home. The chestpiece provides about the same tidal volume as a rocking bed. When people are ill, they usually go from a chestpiece into an iron lung if they have any secretions; if they have none, they may go to mouth positive pressure.

The Poncho

I had a patient who used the poncho at home for long weekends, but he still used the iron lung during the week in the hospital. The poncho was a simpler method of getting him into the body respirator with the assurance that leaks would not develop during the night. However, when high pressure is used, the plastic can work free of the side clips, and leaks develop.

A self-sealing wrap was developed a few years ago, but it did not work as well as expected, and it never became popular. Dr. Norman Braun, a chest internist at New York's Columbia-Presbyterian Hospital, is trying to make a better model, one that is easier to get on and off.

A young lady with one lung, a crushed phrenic nerve on the other side, and a vital capacity of 800 cc made her own poncho. She bought plastic, a Goodyear zipper, cut out the pattern, and put Velcro closures on the knees, neck, and arms. Although she has switched to mouth positive pressure, she still uses the poncho when she is very tired. It is interesting that, with one lung, she needed a negative pressure of -60 cm of water to get a tidal volume of 600 cc. This nighttime ventilation has prevented her from going into heart failure. Before

she started using mechanical aids, she had three bouts of heart failure.

In England, there is a unit similar to the poncho called the Tunnicliffe garment. I have not seen one, but a young lady attending this conference told me about it, and Dr. Spencer will share more information with us later.

Mouth Positive Pressure

When I came to Goldwater in 1957, they had just begun to use the Thompson-Bantam, which is available for the Pneumobelt and mouth positive pressure. It revolutionized the field of ventilation.

Among the mechanical aids for breathing developed over the years are the console pressure ventilators, compact pressure ventilators, and the compact volume respirator (which was not developed until 1978). It is already being used in ICUs for people who have had diseases other than polio. It uses AC/DC current, has an internal battery, and has the advantage of great portability.

We learned in 1964 that, when using mouth positive pressure during the day, holding the mouthpiece becomes a reflex, such that it can also be used during the night. Half the people we know who use mouth positive pressure during the night use the same mouthpiece during the day. They make the mouthpiece available to themselves in one of several ways: by slipping the hose through a hand at chest level, using a bottle holder like that attached to a baby bottle, or by attaching the mouthpiece to a gooseneck directly in front of their lips.

We have also found that the Bennett lip seal or mouth guard can be used at night with the plastic strap that comes with it. We give the lip guard better stability by attaching two canvas straps, about three-quarters of an inch in width, above and below the person's ears, securing it on one side with a Velcro closure.

Recently, a company showed me new headgear which can probably be used with the Bennett lip seal. It gives better stability than straps placed above and below the ears, especially for someone with a moustache or large upper lip, which can cause the lip guard to slip off. This new head harness looks as if it is going to work out very well, and it is available for \$6.50.

Tracheostomy Positive Pressure

Most of our polio patients at Goldwater have changed to mouth positive pressure. The only times we use a tracheostomy positive pressure are (1) when the oropharynx becomes so weak that the individual can no longer hold on to a mouth positive pressure unit, (2) when the air is escaping through the nose, or (3) when the air is just bulging out weak myopathic cheeks and is not getting down into the lungs. At these times we use the tracheostomy with intermittent positive pressure tracheal ventilation.

We most commonly use this type of ventilation for people with myotonic dystrophy, myasthenia gravis, and multiple sclerosis. Another indication for use is when there are recurrent bouts of atelectasis in a person who needs a tracheostomy. That person may prefer to be ventilated through his tracheostomy.

The silver tracheostomy tubes come with an intermittent positive pressure ventilator (IPPV) hose adapter. But today, most respiratory centers have changed to plastic tubes. The advantages of plastic tubes are several: they are lightweight, they have the option of an inner cannula, a cuff, and a fenestration.

At the Manitoba Respiratory Rehabilitation Conference last year, it was emphasized that an individual on "trach" positive pressure during sleep can control the air flow as if he were awake. He can close vocal cords, soft palate, and lips directing the air flow down into the lungs for a deep breath. This is not true when

someone is unconscious, has a weak oropharynx, or is extremely ill. But for the person who is breathing through a tracheostomy, IPPV enables the control of air flow and offers the opportunity to speak. When the volume on the ventilator is increased, the lack of air around the tracheostomy tube enables the person to "leak speak."

The sleeping state is not the same as the waking state. The trouble is that, during sleep, there is some relaxation of the oropharynx, and there may be more of a leak. To compensate, the volume on the ventilator has to be increased a bit more, or you may use a deflated cuff which occupies a small space around the tube.

Glossopharyngeal or Frog Breathing

Glossopharyngeal or frog breathing makes use of the ability of the mouth and throat to act as a pump forcing air into the lungs. To do this, the muscles of the tongue, soft palate, throat, and larynx must be functional. Frog breathing allows time off the respirator, strengthens coughing, and maintains chest wall compliance. Although it cannot be used during sleep, I have seen people use it on coming out of anesthesia. Almost every person who is respirator-dependent uses frog breathing. When his machine stops and he is in that half-state between waking and sleeping, frog breathing begins.

I know of one person who, even before she knew what frog breathing was, used it as her only method of breathing when she was coming out of convulsions. I could not understand why she wasn't breathing and why she wasn't purple. About every 30 seconds the floor of her mouth would go down; she was frog breathing. Three years later I taught her to do it consciously.

The Cofflator

There is one more device I would like

to mention. This is a machine which delivers air under pressure by way of a face mask to the tightly sealed oropharynx. An abrupt release of the pressure with simultaneous chest compression produces an artificial cough.

The cofflator is appropriate for people who are respiratory-disabled and do not have a tracheostomy tube. With this device the proper amount of air flow

for a good cough can be obtained.

The cofflator would be particularly useful for the geriatric population and for people who are mentally retarded. In state schools for the mentally retarded, there are many young people with pneumonia who cannot be handled properly with chest physiotherapy and postural drainage. The cofflator would help in raising secretions.

REACTOR: HEALTH-CARE PERSPECTIVE

Ernest W. Johnson, M.D.

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Much as the severely paralyzed individual has benefited from modern technology, care must be taken that such assistance is appropriate and meaningful to that particular individual, not something forced on him because it is the latest available. It is important for post-polio persons to keep in mind that not everyone in the medical profession is aware of the types of ventilatory aids available.

Basically, there are two areas of need common to people who have had polio or any chronic disease: prospective care and expectant care. Prospective care refers to the health care everyone should have regardless of whether or not anything is wrong with him. Expectant care anticipates what is going to happen to individuals under particular conditions of stress. This is the area that most needs the concentrated energies of the health-care profession.

* * * * *

Technology Serving Human Needs

In Dr. Alba's presentation of some primary technology for breathing, I do not think she made the distinction between the chest and the chest/abdomen cuirass. I think she was using chest to stand for chest/abdomen. We no longer use the chest cuirass because it has about the same low efficiency as the rocking bed.

We now have the technology for environmental control units to assist the severely paralyzed person. Although control units on powered wheelchairs are

much better than they used to be, there are problems with proportional control for people who do not have enough movement.

I would like to suggest that in our increasing reliance on technology we take care that our applications are appropriate and meaningful. I have a feeling sometimes that when the engineers come up with something new, we end up forcing it on people who may not need it. A typical example is "puff-and-sip" wheelchair control. To give that to an individual who has respiratory insufficiency is the height of inappropriateness. [There is strong disagreement about this point from members of the editorial board. Children and adults on ventilators are fully mobile because of "puff-and-sip." One of the editorial board is a member of a rehabilitation engineering team which recommends "puff-and-sip" controlled wheelchairs and other technical aids for people who are ventilator-dependent. -- Ed.]

Prospective and Expectant Care

Let me suggest that there are two areas of need in people who have had polio or any other chronic disease. These are prospective care and expectant care. Prospective care refers to the things anybody should have regardless of what is wrong with him. For example, it means having one's teeth taken care of, eyes and ears checked, Pap smears, and so on. Then we have expectant care; that is, the knowledge and technology to anticipate things that are going to happen to individuals under certain conditions. We

know, for example, that there is such a thing as the late progression of polio. We also know that overwork weakness occurs when muscles are weak. There are degenerative diseases and wear-and-tear phenomena that may occur earlier and more rapidly in individuals whose bodies are weaker than normal and stressed more. The typical example is a person in a wheelchair who uses bifocals, hyperextends his neck to see people from a wheelchair position, and ends up with a pain in the neck.

I just admitted a post-polio patient from Indiana who had a hole in the neck (tracheostomy) because he had gone to a hospital where they had never seen a post-polio patient with pneumonia. He could have been handled without that, but the 'docs' there didn't know about ventilatory aids. I think there is a tendency for us attending this conference to believe that everybody knows about ventilatory aids, but that is not the case. If someone with a respiratory emergency goes to an emergency room, a tracheostomy will be performed unless that someone is awake and says, "Please, don't do that to me." [Tracheostomy is not an emergency procedure for respiratory distress. First, endotracheal intubation will be performed to allow mechanical ventilation. -- Ed.]

Without forgetting prospective care, let us concentrate on expectant care.

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CONSUMER PERSPECTIVE

Theodor A. Dukes

Research Scientist
Princeton University, Princeton, New Jersey

Member, White House Committee on the Handicapped (1977)

Contracted polio in 1945 and is paraplegic

As the aging process diminishes one's functional ability, the technological aids that can help improve one's functions become increasingly important. If consumers are to have access to the technological aids they need, consumers must set the priorities, or they will be set by others who do not know the needs.

Technology can be divided into high and low. High technology requires greater professional expertise and costs more. Low technology is more readily available and is an area of development the consumer himself can effect in a variety of ways. One way is through volunteer work to help provide technically simple items. Another is to encourage student engineers nationwide to design for the needs of the disabled. Another would be to develop inexpensive kits for items that could be assembled at home. The challenge is to make both high- and low-technology items readily available to those who need them. The government cannot be expected to pay for both. What is needed from the government are the life-sustaining, high-technology items, but consumers must exert themselves to obtain at low cost many of the aids they need.

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I am not going to talk about the objectives of this session. Instead, I would like to expand the subject and talk about aspects other than respiratory

problems.

The first question I would like to ask is, "What does technology mean for us?" Obviously we are interested in the mechanisms, gadgets, and even more, in the functions that technology can provide for us. I will talk about some of the problems of technological availability and how that availability might be increased.

Steps to Independence

The most important role of technology is to replace lost functions. The underlying assumption of my discussion is that everyone wants to be and should be as independent as possible. So that we have a framework in which to speak, I have drawn up a classification of what may be considered steps toward functional independence.

Step number one is Life Support Systems. Here belong the respirators, cardiac pacemakers, and kidney machines.

Although others may disagree, I would rank Communication Devices as a second step. Most people who have had polio can talk, but that is not the whole of communication. There must be someone to talk to, and there isn't always. Communication can also be ringing a bell for help, being able to use a telephone, or being able to use a typewriter to put down thoughts and communication in a broader

sense. In the future, there may be devices such as voice writers that will produce a printed copy. That is unlikely to be available within our lifetime, at least, at a reasonable cost, but the technology is there.

The third step is Environmental Control, and we have many items available in this category. We know about switching devices that can turn on a television and unlatch the front door, although they cannot yet open and close a window. This requires something special, but it is already well within the capability of technology.

The fourth step, and the sequence may be somewhat off here, is Self-Care. Not much progress has been made in self-care in decades, but there are two things I can see for the future. One is robotics, the robot arm that can do all sorts of things, and, to my own amazement, the rhesus monkey. I was very much against that idea when I first heard of it, but when I saw a movie about the monkey, I gave the idea further consideration. It was amazing and something not to be neglected because of prejudice.

As far as Hygiene and Dressing are concerned, I have question marks after each. We don't really know what technology can do in these areas, yet they are two of the most crucial steps on the road to independence.

The fifth step is Mobility. This one is pretty well resolved, both indoors and outdoors, except that outdoor mobility is quite a bit more expensive.

The sixth step is Work. Special work stations with adaptations are well within the capability of technology and are already here in the form of computers.

The seventh and last step on the list is Recreation. It is not unimportant, and it is a wide open field for all sorts of variety.

What is the purpose of such classifi-

cations? In my mind each function is a significant step; we can state our goal to be ascending this ladder as far as possible.

Application of Technology in the Aging Process

Why is the technology that increases one's functions important to the aging person who has had polio? We must admit that, although for many years we have thought that we were stable, our functional abilities are in the process of diminishing. No question about it.

For many years, I myself was walking on crutches with two long leg braces, not more than perhaps 50 yards, but it was useful. I could go into a store. I could go to the restroom on crutches, not that I could sit down and get up, but I could go there. Then I found that I took more and more falls. Crutches became more tiring, difficult, risky, and finally just not worthwhile. So, for the last six years, I have been using the wheelchair.

My wife has been in a wheelchair all the time, but a few years ago, she discovered that her arms were weakening and she could not propel a manual wheelchair. She is now in an electric wheelchair -- another step.

We must be realistic enough to think this is not necessarily the end of the road. There will be further weakening. We are in a second phase of polio where we suddenly begin to realize that functional ability will diminish. We will need more help. We will need more devices than we have had, and that is why all of these elements of technology are important to us. We must at the same time know that technology is only one aspect.

High and Low Technology

I would like to arbitrarily separate high technology and low technology by calling high technology that which costs more than \$1,000 and calling low tech-

nology that which costs less. Examples of high-technology items are respirators, kidney machines, and complex wheelchairs. What separates them from low-technology items is that the development process requires professional expertise, which also makes them expensive. Low-technology items include a very wide range of items such as ordinary wheelchairs, reachers, and so forth. These may not need the same standard of reliability or professional knowledge and tend to be resources that are more readily available.

The big question is how we can make both high- and low-technology items readily available. There are increasing needs throughout society for everything. We are part of that increasing need. We are saying that we are aging, and we will need more help from society. At the same time, there is less tax money around. The problem is not only with the federal government -- it is universal. We must set the priorities, or they will be set by others who are unfamiliar with our needs.

Opposition to Creating a Crisis Atmosphere

I am compelled to take issue with the idea of creating a crisis atmosphere. I do not think that is the way to go for two reasons. First, the processes we have been speaking about occur slowly. You cannot make a crisis atmosphere about, for instance, Parkinson's disease. A slow process just doesn't generate that. Second, we are not children any more. It is far easier to identify the crisis about children who have polio or birth defects than, perhaps, adults who have strokes. Stroke affects a large number of people, yet society pulls back from helping them because they are adults. I don't think we can create a crisis atmosphere.

Consumers Setting Priorities in Research and Development

Based on the idea of high and low

technology, we must set our own priorities. We cannot deny the need for high-technology items that are life-sustaining or provide significant steps toward independence. This cuts out a big chunk of available money. But, while these are priority items, they are not the only considerations for independent living. There are many others. As difficult as it may be for us to accept, less funding should be designated for low-technology items.

How can the funds be cut and the means still be provided? Society is used to buying everything with tax money. The money is doled out with the attitude that the government will somehow take care of the problem. But, there are other options.

We must advocate and help ourselves by organizing other solutions (self-help). This is not an original idea, but if people would donate their time for functions that are salaried today -- which is volunteerism -- this might be another option. What it means in terms of technology is that there are many relatively simple technological items that can be provided without great research and expertise. Many items cost too much because the market is too small to warrant development. If the items could be designated, produced, and distributed without paying salaries, they could become available in smaller lots.

How can this be accomplished? Let us consider design as a first goal. Engineering school students are eager to find worthwhile subjects for their design courses and projects. I am suggesting that we provide a focus for their efforts and do this on a regional and national basis. For example, although Princeton's main aim is not design, every year there is a design course. I am often asked to give ideas about what they might do for people with disabilities.

As another goal, design kits could be made using inexpensive parts. These kits should be professionally reviewed and made available in two forms: blueprints

and instructions only, or as complete kits. Fabrication of these kits could be done by volunteers in the neighborhood or by hobbyists on a one-to-one basis who might be glad to do something for a neighbor. Distribution of these kits shouldn't cost much money if done on a regional basis by volunteers, perhaps by people who have had polio. We should look for an umbrella organization like Easter Seals or the March of Dimes.

A volunteer operation naturally poses certain problems. The first is liability; there will be risks. The second is reliability; critical items must not be built. The third is competition; this could cause a loss to some businesses. It is a long-term plan, but if action is taken now, in a few years we could have an organization.

Lastly, we should be concerned with

the identification of need. We are the ones who have to identify the need. Everyone here who has had polio or is related to someone who has had polio, in a wheelchair or not, knows the kind of technological devices which today are either too expensive or nonexistent, that could make an improvement in his or her life.

Summary

We look at technology in terms of the help it can provide for our attaining increased functional ability. We have said that we must have high-technology items. There is no choice. Society should pay for them. In low-technology items, we should organize volunteers for design, fabrication, and distribution. I firmly believe that we, the people who have had polio, can be leaders in working out this process.

REACTOR: CONSUMER PERSPECTIVE

Herbert S. Merrill

Engineer, State of Maine

Member, Rehabilitation Council, Falmouth, Maine

Contracted polio in the 1950s and
requires respirator assistance

Those who have had polio and use ventilator equipment are experiencing critical problems with the maintenance of their equipment. Replacement parts are very expensive because they must be custom fabricated -- a service that is not approved by third-party payers. There is a need for more research into the transfer and adaptation of available technology to provide products for people with disabilities.

* * * * *

Problems of Ventilator Equipment Maintenance

First, I will talk about equipment that affects approximately 20% of the people who have had polio, namely, ventilator equipment. The technology of ventilators is no longer a problem. The real problem occurs after the initial life-threatening situation is over and the person has returned to the mainstream. The difficulty lies in maintaining the original equipment that people have used since the fifties and sixties. [Mr. Merrill is using a cuirass ventilator. -- Ed.]

A commercially significant demand for the original equipment (Monaghan iron lungs) or the parts to maintain them, no longer exists. Custom-made equipment and parts are costly and are not approved or paid for by third-party payers, such as Medicare and the Veterans Administration. The problem then is a financial one.

To the users of ventilator equipment, it is a crisis.

Adapting Available Technology

The second part of my discussion deals with the possibility of adapting modern technology for use by people with severe disabilities.

Consider all that has happened with NASA and in the fields of electronics and computers. Many electrical and mechanical devices have come to the fore in the last 25 years, and many of these could easily be converted to the needs of the disabled. Devices like television, word processing machines, and videotape recorders could be adapted, but it will cost money.

The products available to people with disabilities have not kept pace with the state of the art. For example, there is a means of paging my attendant which allows him the freedom to go outside. My attendant carries the unit in his pocket. I can reach out, press a button to activate it, and it will send a beeping signal. He can pick this up and respond to it. The unit is called the Mobile-Alert and is available from Radio Shack for \$69. [The Mobile-Alert can be modified for people who cannot push buttons. The cost, according to the 1982 Radio Shack catalog, is \$99.95. -- Ed.]

At present, there is not enough re-
search money allocated for these types of
projects. Rehabilitation centers should

fund fundamental research into simple
ways of adapting commercially available
equipment.

ORGANIZATIONAL PERSPECTIVE

Carlton Bishop

Representative, LIFECARE Services, Inc., Augusta, Georgia

The types of ventilator equipment developed in the 1950s and early 1960s are still in use by people living independently. Successful long-term use of this equipment is due to the simplicity of its design which facilitates its use by lay people. The complexity and sophistication of modern technical aids are disadvantages for the independent user.

There is a need for greater personal involvement and understanding on the part of professionals concerned with the treatment and care of people with respiratory disabilities. Regional training centers for respiratory therapists are needed. Also needed is a combined effort to obtain all available resources and seek out those services that will be most beneficial.

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Advantage of Earlier Ventilation Equipment

We have what is known as the March of Dimes Respirator Equipment Pool in Augusta, Georgia. It was originally started in 1961 and has carried on much the same function over the years. I have also been affiliated with LIFECARE Services for the last 13 years, and we have a great working relationship.

The question has been raised about whether we can utilize the situations, techniques, and practices of the late 1950s and early 1960s in our present-day situation. The answer is that in a number of instances earlier techniques are being employed today, not only by people who had polio but by others with breathing-related problems, such as muscular dystrophy, ALS, spinal cord injury, etc.

Emphasis is once again being given to negative pressure inhalation because it has proved to be a safe ventilation method since the early days of polio. For example, the iron lung is one of the most efficient and restful types of ventilation, but not everyone can use the iron lung. Other types of negative pressure ventilation include chest units, wraps, and the rocking bed. Let us not forget, too, the positive pressure breathing concepts which can be utilized by mouthpiece, trach, Pneumobelt, and mask.

Two important factors we should note here are that the types of equipment developed in the fifties and early sixties are still used today, and it does not take a trained professional to operate this equipment. Largely because of the simplicity of design, people can use this equipment at home following easy instructions. This is very important to the person returning to a normal home situation and beginning independent activities.

By contrast, most of the equipment currently used in hospitals is too sophisticated to allow this. It lacks portability and is complicated to the degree that trained technicians are required to operate it. Yet, we should be openminded toward accepting new technology and new concepts. There are several advantageous devices available that use modern technology. These include environmental controls which help people answer the phone, turn on the television, and so forth.

Apart from the technology and resources available, I believe that we still are missing a vital ingredient in certain areas of the health-care system: the personal involvement and personal understanding of the professionals involved in

the treatment and care of disabled individuals. Disabled individuals are not asking for anything special; they don't want pity. They want to be heard. It is a common occurrence for an individual who has had polio to arrive at a hospital in respiratory distress and no one realizes that the person's lungs have been damaged from polio, either because they didn't hear it stated, or didn't bother to inquire. Also, it should not have to be pointed out that a respirator must be plugged in, if the person is to breathe. Another attitude that is frequently met occurs when the therapist asks the person who has had polio, "What kind of Mickey Mouse equipment are you using?" Little do they know that it has kept that person alive for years.

Social workers are supposed to get involved with the families of people who have had polio, as well as those who are spinal cord-injured or have other respiratory problems requiring artificial ventilation. It is the social workers who are responsible for working out systems for getting those people home. They must become involved in working out home ventilation programs and getting financial support. Yet, they are surprised when a person can go home with a ventilator. Most of the care personnel in hospitals believe it is impossible. I can give the names and addresses of thousands of people who did go home.

Regional Centers to Expand the Professional's Understanding

This is a very important area of concern. We need awareness and sensitivity training. We should also do everything possible to educate those people who need to be familiar with ventilators and are not. I know Dr. Alba at Goldwater and the efforts that are made there. Unfortunately, we do not have these types of centers in all parts of the country.

About four years ago, I and an instructor in the Respiratory Therapy

School of the State of South Carolina started such an educational program. We now have several classes coming through our facility each year. These classes include respiratory therapy students, nursing staff, and other interested personnel. It is only one of the many ways we can use to meet the educational problems that exist today.

By visiting our center, professionals are becoming aware of what is available, what it does, and how to obtain it. They learn this by actually trying out equipment like the iron lung, the chest shell, the Pneumobelt, and mouth positive pressure machines. The result is that when a respiratory-disabled patient comes into their hospital, the staff is familiar with the equipment, knows what the situation is, and knows how to handle it.

Combining Resources for Beneficial Services

I have been asked what I would do to improve the present-day situation, drawing from my past experience. That is a hard question to answer.

We are using, in every way possible, everything we have available. However, there are other barriers involved, one of which has been mentioned numerous times in this session, and that is funding. How does someone get the funding for the devices, the respirators, or whatever it is that is needed?

There are resources available today. The March of Dimes is one; the Muscular Dystrophy Association is another. But even with all the effort these organizations give to the situation, there are still many unmet needs. I think we need to set an example and a goal to obtain all the resources available to handle these respiratory needs, with the priorities that Theodor Dukes listed. We should combine our efforts with those of others to seek the most effective means for providing truly beneficial service.

REACTOR: ORGANIZATIONAL PERSPECTIVE

Robert B. McCown, Ph.D.

Staff Scientist and Engineer,
Intermagnetics General Corporation, Albany, New York

Contracted polio and is quadriplegic

From the consumer's point of view, there are three basic considerations in the design of technical equipment: that it will be durable, that it can be easily maintained, and that it can be repaired anywhere.

The principles of designing to cost are well known, but they are rarely practiced. One way is to design to required performance standards, without overspecification. Other cost-cutting measures include the use of standard parts and subassemblies, low-cost materials, and modular design. The advantages of this design approach are several: each person can custom assemble parts to suit his needs, delivery time is shortened, and repairs and alternatives are facilitated.

Design approaches to be looked at seriously are those utilizing commercially available products and those that are simple enough for anyone to operate and maintain.

* * * * *

Consumer Need in Design of Technical Equipment

I find it rather ironic that we are gathered to talk about using space technology for those of us who have absolutely no possibility of ever getting into space! NASA did a very good job of designing equipment -- at any cost -- that was extremely reliable for a short period of time. They were going to the moon and leaving specially designed equipment

there. But this is not the approach to the design of equipment that we need here. The space-walker wheelchair that NASA built is an example. A wheelchair was promised that would revolutionize the design of wheelchairs. It would go over any terrain, up curbs, have extreme flexibility, and so forth. They built one fast and beautiful piece of equipment that only cost \$100,000 a unit and operated a few hours before it ran down. In addition, this wheelchair did not fit in a standard-sized bathroom, and one had to have a master's degree to operate it.

What we need is equipment that can be repaired anywhere, that is going to continue running for years, and is easily maintained in any environment.

I would like to contrast the experience of the space-walker wheelchair with the first positive pressure breathing apparatus in 1955. It was homemade. A person came into the respiratory center carrying a positive pressure breather that he had built from a canister vacuum cleaner. He had adapted a valve from the mouthpiece of scuba diving equipment. It was very simple. The air blew at a very slow rate and low pressure to expand his lungs. He had to let go of the mouthpiece in order to breath out again, but it accomplished what he wanted. It was repairable in any little town in the country. He could take it into the local appliance dealer and get the thing running again. Unlike the custom-designed wheelchair, the positive pressure breather was built with standard vacuum cleaner and

scuba diving parts that any technician could repair.

Usually, we have problems with equipment designed in academic centers. Graduate and undergraduate students are low paid, so labor is cheap. Parts and material costs are kept to a minimum because they are working under cost constraints. If they buy a single piece of steel and have a graduate student spend five days machining it into the right form, they will have something that works fine. But when one tries to manufacture that product, the cost becomes extremely high.

Principles in Designing to Cost

Typically, market-oriented engineering starts with a design idea provided by production engineers in the consumer market. Then the company will assign two or three engineers for a whole year to the task of trying to cut the cost of production by 10¢ per unit. This might seem to be a small savings, but by making a million units, one can save \$100,000. [The scale of production for most technical aids for people with disabilities does not indicate a saving. -- Ed.]

The principles of designing to cost are very well known, but not usually practiced. One way of designing to cost is to design to required performance without overspecification. In other words, build the equipment to do what you want it to do and no more. The positive pressure breather which only inflated the lungs was all that person needed and no more.

Another way to design to cost is to use standard parts and standard subassemblies that are made in large quantities. Modular design and the use of low-cost materials are other cost-cutting factors. For example, an electric wheelchair could have the wheel drive mechanism and batteries in one unit and a seat bolted to that. But there could be available three different seat sizes. There could also be several standard size arm and leg

rests to choose from and seat backs of different heights. A powered recliner back and several kinds of control systems could be offered. Control systems might include a manual tiller, a powered tiller, a joy stick, and maybe one of the new sonar-type controls now being developed.

What can be accomplished by using this kind of wheelchair design? First, it would lower the cost. Instead of having a special custom-made wheelchair for each person, a selection of standard subassemblies and parts could be put together in combination to suit each individual. Second, it would shorten the time of delivery. Instead of ordering a wheelchair which takes months for delivery, the dealer could bolt together a custom chair in several hours. Third, this kind of design approach permits easy repair. If a wheelchair unit breaks down, fast repair is possible because one can simply replace that unit without replacing the entire chair. Fourth, the configuration of the wheelchair can be easily changed if the capability and habits of the occupant have changed. For example, as a person gets older, he will need a rest during the day. One could just take off the old back and add a powered recliner.

In addition to all of these benefits, if standard attachments for the various units were developed, a person could have power driving from one manufacturer, seats and backs from another, and power controls from a third. Standard attachments would help produce two additional benefits, namely, a variety of options for the consumer and competition, which would lower prices.

Design Approaches to Meet Need

We all are aware that we are facing an era of electronic devices for the consumer market that the disabled can use. Right now on the general market there are available remote light and appliance controls. This market is expanding very rapidly. Automatic doors and windows, heating and cooling systems are operated

by remote control. Remote control televisions and stereo systems are all now available from major manufacturers.

This market is expected to increase so rapidly that industry giants, such as Phillips and Norelco, are trying to set international standards so these devices can be compatible with each other. For example, a window opener from one manufacturer could be operated with the control from another manufacturer. These devices are going to be on the market at low prices in the next two or three years. Many of them are being introduced now. Devices designed for the general consumer market will be available that will allow severely disabled people to live more independent lives.

I would like to end by pointing out that there are two design approaches that we should look at very seriously. First, we must utilize as many items built for the general consumer market as we possibly can because they are designed for the lowest cost and the highest possible benefit. I was pleased, for example, to see that an ordinary suitcase was used by Thompson in the design of its respirator. The suitcase is a mass commercial item and obviously reduces the cost of the respirator. Second, we need to utilize the design approach used by IBM, called KISS (Keep It Simple Stupid). It means just that! Keep the equipment so simple that anyone can use it. In keeping it simple, it becomes more reliable, less likely to break down, and more easily repaired by anyone anywhere.

GROUP DISCUSSION

HOW CAN WE APPLY "SPACE-AGE TECHNOLOGY" TO MEET HEALTH-CARE NEEDS IN A CLIMATE OF "LIMITED" RESOURCES?

Eugene Murphy, Ph.D.

Director, Office of Transfer,
Veterans Administration, New York, New York

Contracted polio in the 1920s

The Rehabilitation Engineering Society of North America (RESNA) is three years old and has sponsored one formal rehabilitation engineering meeting on its own in succession to government inter-agency meetings.

RESNA makes a point of consumer involvement. Margaret Pfrommer was, for example, the Everest and Jennings Lecturer at the 1981 meeting in Washington (1981 Everest and Jennings Lecture, COPH Bulletin, 4th quarter, 1982). It is an organization whose membership includes physicians, engineers, therapists, providers, and manufacturers, with a provision that at least a third of the Board of Directors be disabled individuals.

There are rehabilitation engineering programs under several government agencies in various centers, both within the agency's own facilities and in university projects and research contracts. In Chicago, the Rehabilitation Engineering Program is part of the Northwestern University Medical School. When new equipment for respiratory aid is needed, one might collaborate with the Harvard-MIT-Children's Hospital of Boston Rehabilitation Center. Phillip Drinker, the son of the original iron lung inventor, is very involved in this center's work.

Is there anything unique about aging polio survivors that calls for equipment that would not otherwise be required for

younger, more vigorous people? I am not sure that there is. Can existing equipment be adapted in cooperation with developers concerned with disabilities like muscular dystrophy and spinal cord injury? Apparent competition with them would be devastating in this period of limited funding. We do not want to present a divisive influence when we really need a group approach.

We should try to develop new adaptations of commercial equipment and devices coming out of the rehabilitation engineering programs for other purposes. Consider, for example, commercial devices. Several people today have mentioned the small electronic devices which permit commands over household electrical wiring to perform functions such as turning lights on and off, dimming lights, operating various controls, or even signaling an alarm in another building served by the same transformer. Dave Rye of BSR (USA) Limited had a technical note in our Bulletin of Prosthetics Research (autumn 1980) about this type of commercial control and his adaptation which enables a person to operate the control device with low pressure switches -- "puff-and-sip."

Other basic elements, low in cost and developed for the mass market as luxuries, are adaptable for disabled individuals. Historically, this kind of technology transfer has occurred throughout the

automobile industry. Devices like the self-starter, automatic transmission, power brakes, steering, and so on, originally developed for the general public, turned out to be solutions which permitted more and more people with disabilities to drive.

A contest was mentioned as a way of stimulating incentives for private inventions, including student developments. The Johns Hopkins Applied Physics Laboratory had a contest last year, sponsored by the National Science Foundation and Radio Shack, and with participation from a number of companies, to develop new computer uses to aid people with disabilities. A special issue of the magazine Computer, published by the Institute of Electrical and Electronic Engineering (IEEE) last spring, launched the contest with a series of disability categories. Several of the devices offered were for the orthopedically handicapped, but many others were for people who are blind, deaf, dyslexic, and so on.

Manipulators have been mentioned as a possible device for people who do not have use of their arms. Several research groups have worked on manipulators and robotics, among them The Johns Hopkins Applied Physics Laboratory, which has made considerable progress in recent years working mainly with people who are spinal cord-injured. They have integrated a worktable, computer control, and more. Larry Leifer at the Veterans Administration Hospital in Palo Alto and Stanford University is particularly interested in robotics.

A big problem is cost. Nowadays, we are dealing in kilobucks and megabucks, so emphasis must be placed on the need for simplicity of design. Most important, however, is recognition not only of the design of devices but of overall systems.

Panel Recommendations

1. Create a consumer report magazine for consumers who have disabilities.

This report should involve consumers in establishing standards for the testing and design of products they use. These standards should include those qualities essential to the successful use of a product, that is, simplicity of operation, ease of repair, and product durability.

2. Gather existing information on technical aids into an integrated format for dissemination to both consumers and manufacturers. This information should include sources for purchase of equipment and repair manuals for data on interchangeable parts.
3. Establish a mechanism for the consumer to become directly involved in ordering his own technical equipment even though the purchase is made by a third-party payer.
4. Work to change the policies and practices of third-party payers to include consideration of purchase of custom-made devices if they are necessary.
5. Establish an information referral system (800-12P-OLIO) that can be used by people who have had polio, the professionals who serve their needs, and any other interested people.
6. Encourage the March of Dimes to again use their organization's resources to help focus media attention on the present concerns of people who have had polio.
7. Establish a working relationship with the NASA Office of Technology Transfer and other engineering groups to utilize modern technology to develop solutions to meet the specific needs of people who have had polio.
8. Create a group that would function either independently or within the structure of an existing organization as a resource in such activities as lobbying and public relations.

9. Standardize respiratory and other equipment to ensure its use and repair anywhere in the country or world.
10. Focus attention on the need for engineering services which deal with the development, application, and adaptation of technical aids to meet the needs of people with disabilities.
11. Provide incentives to small companies which cannot afford to manufacture technical aids for people with disabilities. Incentives might include a national award or competition and/or seed funds.
12. Encourage those agencies, departments, organizations, etc., that play a role in the provision of technical products and services to utilize existing consumer and professional publications to communicate who they are and what they do.
13. Compile lists of equipment and design needs and send them to engineering schools to be used as ideas for projects. Small cash awards could be given as recognition for such things as completion of a project or for designs that are adaptive rather than customized.
14. Obtain guaranteed sales by combining commitments from a large number of groups, such as the Veterans Administration, so that manufacturers can produce new products on a cost-effective basis.
15. Utilize the people attending this conference to identify health problems. Conference participants consist of people who have had polio and professionals in the health field.
16. Emphasis should be placed on regional centers whose services would include a hotline, the availability of special devices, and dissemination of special expertise and information to both the medical professionals and

people who have had polio.

17. Expand the concept of technology to include medical technology, that is, not only electronic aids but items like biofeedback.

Additional Comments

Dr. Allen Goldberg

I want to respond to the suggestion to organize another meeting. It is quite obvious that we want to have a general working meeting now in order to come up with some objectives and plans of action for applying the information we have gained here. Action is something that this Planning Committee wants to guarantee. We anticipate future conferences sponsored by other organizations that will focus specifically on medical, consumer, and organizational aspects. We already have scheduled three full days. But, if you have the energy -- and you have proven to me beyond a doubt that you have -- then certainly we will find the way for people to have additional meeting time and space. I knew this conference would generate more interest and more group action. [An informal meeting was held later that evening for many hours. -- Ed.]

Margaret Pfrommer

Since my name was mentioned a couple of times here, Allen Goldberg gave me the opportunity to clarify some things. I am in the field of rehabilitation engineering, a consumer, and a volunteer in any way that I can find to be helpful in the proper application of technology. I am Chairman of the Consumer Involvement Committee of the Rehabilitation Engineering Society of North America (RESNA). Dr. Murphy explained what RESNA is all about. We have two other members of that Committee here as participants today, Tom Schworles and Valerie Brew Parrish. During the group

session, I thought it appropriate to volunteer our Committee's involvement in carrying out some of the proposed actions that will come from this conference.

Three consumer articles were published in the 1981 Rehabilitation Engineering Conference Proceedings, one dealing with problems within rehabilitation engineering involving physically disabled people, one involving blind people, and one involving deaf and hearing-impaired people. These articles give an idea of what the consumer thinks is good and bad in the engineering field today. The same three articles are also published in the 1981 summer issue of the COPH Bulletin.

Also, there is a yearly student design competition, the awards for which are presented as part of the activities of the Rehabilitation Engineering Conference. Perhaps we could get information out to the various schools participating in the competition that there is a particular need, if one has been identified. Our Committee wants to represent the interests that are truly yours. We do not want to take it upon ourselves to suppose that you need or want something. People who

have had polio are supposed to be great for going out there and doing it themselves. Do it again! Tell us what you want and how rehabilitation engineering can be beneficial to you.

Finally, I want to stress that ventilator-dependent people can operate chairs by "puff-and-sip." Not much breath is needed, mostly breath control. If ventilator-dependent people can drink water through a straw, they have a good chance of successfully using a "puff-and-sip" control.

John O'Connor

My 22 years of involvement as legal counsel for the March of Dimes have been limited to the respirator equipment program via phone contact and correspondence. We have heard several good suggestions here this morning, including returning to the March of Dimes for expanded assistance. Upon the completion of the transcript of this conference, I will present it to the executive staff in our national organization. Perhaps with our continued endeavors, some of these fine suggestions will materialize.

SESSION IV

**THE PRESENT: THE REGIONAL APPROACH TO MEETING NEEDS
OF POLIO SURVIVORS OUTSIDE OF THE
MEDICAL CENTER**

OPENING REMARKS

Thomas R. Schworles

Chairman, Education Committee, Illinois Congress
of Organizations of Physically Handicapped, Chicago, Illinois

Has Werding-Hoffman Syndrome and is quadriplegic

An Effort at Synthesis

We have a very important challenge. In this fourth session we must bring together thoughts and ideas of the earlier sessions, repeat them, highlight them, and bring them toward better resolution and clarity. I hope you can think of this as an effort of synthesis.

We are talking in this session about alternatives to the hospital, to the institution. We would like you to deemphasize in your minds the idea of "medical care." We are talking about people who do not want to be patients, people who do not want to be always thinking of their lives as having health-care needs, and people who may have needs very similar to others who are not in hospitals.

We are asking that we think of the welfare and benefits not only of people who had polio and are still coping with it, but people who share similar concerns because of respiratory insufficiency. There is a wide universe of people like you who have the same concerns. There-

fore, if we come up with ideas, programs, and strategies which are going to benefit some of the constituents we have talked about for two days, we are also going to benefit many more constituents.

Regionalization of Services

We are talking about the concept of regional services. We want to know what the regional activities and strategies are that can get people out of the institutional mold. We are asking about the kinds of organizations we need on a regional basis to create a life that is concerned with more than medical and health care.

We have heard from scientists, engineers, physicians, and health-care people. The prostheses and techniques are there. The information is there. The money is there, too. And the people who need the services are there. What we need to know is how to tie it all together. This session's focus is on the way this can be accomplished.

HEALTH-CARE PERSPECTIVE

Geoffrey T. Spencer, M.B., F.F.A.R.C.S.

Phipps Respiratory Unit, South Western Hospital

Consultant, St. Thomas's Hospital, London, England

The response to the polio crisis in Britain and northern Europe laid the foundation for the development of technological and organizational advances in respiratory and intensive care since the 1950s.

A new category of people developed -- beneficiaries of intensive care who, because of their need for life support, had nowhere to go after leaving acute care centers. Polio survivors played a catalytic role in generating awareness for home care services which now have been applied to helping others with technology dependence.

Both institutional and community-based resources provide services for people who have benefited from advances in medical care. Through analysis of a patient's respiratory disability, general disability, and home situation, a decision can be made on an individual basis as to the preferable and most cost-efficient program.

A three-year follow-up study described the degree of success in returning patients home and assessed the relative cost of home and hospital care. This study is based on experience with polio survivors as well as those from intensive care now on respirators and receiving home care.

* * * * *

Setting the British Scene

The practice of medicine and the history of polio are so different in Britain

that I am compelled to supply you with some background. I am sure you have a rather prejudiced view from some of the things you have heard and read in the newspapers. I need to set the record straight so that what I have to say about getting the ex-patient home will be meaningful to you and you can make sense of my contribution here today.

We have a National Health Service, which means that all medical treatment is "free" for everybody, whether it is long-term or short-term. [The service is paid for through taxes. -- Ed.] I know you would call that socialized medicine, but it has really nothing to do with politics. It is a national medical service. Clearly, I am a government employee and therefore expected to be an inefficient, expensive, slothful bureaucrat, providing bad medicine for a disinterested impersonal state organization rather than for the patient.

In reality, it is clear to me from talking to the doctors here in the last couple of days, that I have far more professional freedom than most of them do. That may sound surprising, but I do assure you it is true. The more I think about it, the more I find my degree of professional freedom very difficult to believe. Let me state three things.

First, when the National Health Service started in 1948, the doctors only agreed to join it because they were given three freedoms: to prescribe whatever medicine they thought necessary, to practice medicine as they thought best, and to publish their results regardless of whether

they were favorable or unfavorable to a particular government or state organization. As an example, I can prescribe any respirator for the use of a named patient in exactly the same way as I can prescribe an aspirin tablet.

Second, the members of the general public were given the right to choose their own general practitioner, and the general practitioner had the right to choose the specialist to whom he referred his patients. If the specialist happened to be at the other end of the country, so be it. The Health Service had to pay the bill, including transportation. A patient can insist that he be referred to a particular consultant and that he be taken away from one consultant and referred to another, but he does not consult me directly, and it would be wrong if I were to accept a patient without a referral.

Third, there is no time limit on provided medical care. This is of particular value to those with long-term or chronic illness who need medical support or treatment either continuously or from time to time during the course of a long-term illness.

I do not mean to give the impression that the National Health Service is perfect. Its main disadvantage is that people wanting elective minor procedures, such as hernias and varicose vein operations, may have to wait five years to have the operation done, which is why a portion of these people are still prepared to pay quite large sums to have the surgery done privately.

History of Polio in Britain and Northern Europe

Until 1952, the history of polio in Britain and northern Europe was very similar to the story that we have heard described in the past two days. In 1952, there was a very important event in Copenhagen, a bad epidemic of severe paralytic polio, many of the cases being bulbar [paralyzing the center of

breathing -- Ed.]. The patients kept coming, and we ultimately ran out of iron lungs and didn't know what to do.

So we got some anesthetists to come and make holes in patients' necks [tracheostomy -- Ed.] and do what they call "bag ventilation [inflating the lung by hand -- Ed.]. They appointed and paid medical students a small sum to squeeze the bags. After three months of this, it was quite obvious that the "lucky" ones who arrived early enough to get iron lungs had a mortality rate of about 80%. Four out of five of them died. The unlucky ones who arrived late enough to receive only bag ventilation had a mortality rate of about 40%.

The Evolution of Respiratory Care for Long-Term Ventilator-Dependent People in Europe

The Copenhagen experience made a great difference to the practice of artificial ventilation in Europe. Since then, we have concentrated much more than the United States has on developing and perfecting the techniques of long-term artificial respiration by intermittent positive pressure [via tracheostomy -- Ed.].

We have greatly simplified tracheostomy care at home. For example, sterility or even cleanliness in the home is totally unnecessary. Most patients have two or three favorite suction catheters which are kept in the rinse water together with all of the phlegm that has been sucked up. By the end of the day, they are so slippery they slip down the trachea nicely, but are difficult to hold in bare fingers. After they are picked up off the carpet, they go back into the trachea. When I first saw this, I was so surprised I managed to persuade our professor of bacteriology to make a few cultures of the rinse water. He grew that well-known organism, "amorphous debris," and nothing else. In the hospital, techniques such as this would cause terrible cross infection, but in his own home, the patient lives with a happy symbiosis of his own bugs,

and it doesn't really matter whether suction catheters are clean or not.

I got into this field from acute intensive care. I was called on the staff at St. Thomas's Hospital in 1965 to run the new intensive care unit. This was a period when high-technology medicine was fashionable and money for it flowed readily. Within a short time after starting the unit, I realized that improving the techniques of artificial respiration had serious consequences. Not all the patients for whom it could be used recovered fully, or they died, despite our new-found expertise. A few remained alive and fully conscious but did not regain the ability to breathe for themselves. They remained respirator-dependent cripples resembling in many ways the severely disabled polio survivors from the previous decade.

A New Mission for Existing Facilities and the Establishment of the Standard Care

We believed it necessary to try to rehabilitate these hapless victims of "sophisticated" medicine, and in 1967 I got an opportunity to take over Dr. Kelleher's old polio unit and transfer the remains to one of the outlying hospitals in the St. Thomas's group. We inherited 18 patients, 10 of whom had managed to leave the hospital and live at home. We also inherited the key staff, which was just as well, because at that time I knew nothing at all about polio and its respiratory management. The most urgent need seemed to be to establish a home maintenance and support service for respiratory and other equipment. With home renal dialysis, this idea is familiar enough today, but in 1967 it seemed rather radical. We bought a van and employed three engineer-technicians, a social worker, and a senior nurse to provide home maintenance service. We soon discovered this was meeting a real need, and other polio survivors wanting this service started to appear. [This demonstrates that the need for services increases with quality of care. Today's intensive care medicine has created new needs. As we create new services, more

people will ask for them. -- Ed.]

The Creation of a Health-Care Crisis - The "Disease of Progress"

Within two years, it became clear that this wasn't a small problem. Sixty or 70 people with the aftereffects of polio, some with breathing difficulties and some not, had crept out of the woodwork and found their way to us. They wanted home maintenance service for their equipment. So what I thought was a quiet little place to retire very quickly became a major part of my work. It also transpired that as intensive care improved, every intensive care unit had similar problems with a few people left who were stuck on respirators.

Some of the better-endowed respirator users (responauts) had already succeeded in leaving the hospital. With the number rising as a result of "improvements" in intensive care, the next problem was what to do with those without any or sufficient family to be able to take on their own home care.

The Stimulus for Home Care Service - Self-Help

Most, but not all, patients wanted to live independently. They started a campaign stating that it was cheaper for the state to support them in their own homes than to keep them in hospitals. As all hospital care is available under the Health Service, by going home with state support, they would save public money, be happier, and lead fuller lives. They put their iron lungs back on the trucks, marched to Number 10 Downing Street, and handed in a petition. After some arguments and a visit to our unit by Richard Crossman, then Minister of Health, the Ministry set up a "research project" to assess the relative cost of home and hospital care. It wasn't research, because we all knew the answer -- it was termed "research," however, for political reasons, so that special services

provided by the project for respirator-dependent people wouldn't set a precedent enabling other categories of severely disabled people to claim similar special consideration.

The Pilot Study of Home Care Services

The project lasted three years, and I am delighted to say that Dr. Kaufert, who was with us for some of the time near the end of the study period, is with us here today from Winnipeg. We soon found that we had to categorize the subjects in two ways:

1. The severity of respiratory disability.
 - Grade I - Those able to breathe spontaneously except when they had a chest infection or other inter-current illness.
 - Grade II - Those regularly needing a respirator to sleep at night.
 - Grade III - Those needing a respirator at night and some mechanical breathing aid during the day.
 - Grade IV - Those needing fully controllable artificial respiration continuously.

2. The severity of general disability.
 - Grade I - Those who could walk.
 - Grade II - Those who could propel their own wheelchairs.
 - Grade III - Those needing a power-drive chair.
 - Grade IV - Those totally paralyzed in all limbs.

We had to find out how much family support was available, whether there was a wife or husband, a daughter or son, a mother or somebody to help in home care. To get patients to participate in this study, we had to promise that, at the end of the study, the resident attendants with whom they had been provided would not be withdrawn.

Our study soon showed that the subjects who were Grade IV in both categories with no family assistance were more expensive to tend to at home than in

the hospital. They needed three resident paid attendants. However, as soon as there was one factor in the patient's favor, a Grade III somewhere, then it was cheaper. If a patient had more than that in his favor, say a Grade II throughout or family assistance, it became very much cheaper, and they were happier at home.

To enable our subjects to live at home, we employed 17 paid resident attendants. The patients preferred untrained people whom they could teach to do things their own way, like tracheostomy suction, rather than receiving a technique imposed by professional personnel. We paid the attendants a reasonable living wage, board, and lodging [The equivalent of about \$175 per week. Good pay is vital. -- Ed.].

Apart from showing cost benefit, the study emptied our 16 inpatient respiratory unit beds. That didn't save any money because they filled up with other similar patients who came from elsewhere with similar problems.

The Growth of Home Care Services - The Definition of Need

The original study involved 25 patients. Since that time we have had 700 referrals, of which 282 have gone home with their respirators. About 70 have died, and we have been able to wean the others from their machinery. We are the only unit in the country set up primarily to provide this service, which means we are covering a population of about 25 million. There is no doubt that the techniques of weaning people with respiratory insufficiency from tracheostomies and respirators are not as widely understood as they should be.

We now have 160 home respirator users in our four respiratory categories. The area we cover extends from Warsaw (Poland) to Scotland, all the way down England through Wales to the western peninsula, with one or two in Ireland and elsewhere.

Some Details about Home Care Services and How They are Provided

We have three technicians and an engineer who drive 75,000 miles a year doing regular home visits. But they do a lot more than maintain equipment -- they tell us how the patient is progressing, and they know all the patients by name. I rely on their expertise to tell me if things aren't going quite right.

The patients have immediate access to the unit by a telephone hotline. All our

patients are given telephones, usually partly paid for by their local authority, and we ask they not use it simply to report the need for spare parts.

We employ 17 paid resident attendants whom we share among those patients whose family support is insufficient for their needs. They are untrained people and, although they live in the patients' homes, they are employed as hospital staff. The chart shows the numbers and distribution between our four grades as of July 1, 1981.

Home Respirator Users (at July 1, 1981)

| | <u>Poliomyelitis</u> | | <u>Nonpolio</u> | |
|--------------|----------------------|-----------|-----------------|-----------|
| Scoliosis | Grade I | 6 | Grade I | 5 |
| | Grade II | 21 | Grade II | 12 |
| | Grade III | 14 | Grade III | 8 |
| | Grade IV | 2 | Grade IV | 1 |
| | | <u>43</u> | | <u>26</u> |
| Nonscoliosis | Grade I | 7 | Grade I | 2 |
| | Grade II | 17 | Grade II | 6 |
| | Grade III | 12 | Grade III | 4 |
| | Grade IV | 13 | Grade IV | 2 |
| Totals (132) | | 92 | 40 | |

The Technology

Finally, I must tell you something about the apparatus we use, because some of it is quite different from what you use in this country and it has its advantages and disadvantages. The first major difference is that we are not horrified by tracheostomy, as I think you in the United States are. As you see from the chart, we have 18 Grade IV patients at home receiving continuous artificial respiration via tracheostomy. They use a very simple intermittent positive pressure machine consisting of a small concertina-like bellows on top of which a weight drops to drive air into the lungs at each breath. The weight is lifted up with the bellows between breaths by a small electric motor driving a bicycle chain through a three-speed bicycle gear box with a freewheel to allow it to fall. A spare sprocket wheel is also connected to the chain and is driven by a 12-volt motor. By changing a knob, the machine will run off a battery or electrical current.

The machine is simple and very reliable. An even smaller version with only a 12-volt motor is incorporated beneath the seat of a special wheelchair respirator which is equipped with a self-contained suction apparatus. The chair was designed by a patient who has lived in one for the last 20 years, which is why it is so well suited to its purpose.

We use these respirators with non-cuffed silver tracheostomy tubes so the patient can talk during inspiration, which is especially prolonged so that speech can

be virtually normal. Indeed, I regularly ask one such patient to lecture to medical students and doctors. He can talk as loudly as he wants just by putting an extra weight on the bellows.

Our iron lungs are also quite different from yours. The top half hinges open from the foot end so that the tank opens up like an alligator's jaws. This saves space at home and makes getting in or out very quick and easy. There is also a modification of the alligator tank in which the whole tank can be made to roll over lengthways, so that the patient lies comfortably on his front while secretions drain from the lungs.

We use cuirass shells more often than you do, and we make most of them to measure from a plaster of paris cast of the torso. This is particularly necessary for patients with scoliosis.

A Final Word about Scoliosis

Much nonsense is talked about the prevention of scoliosis following an acute paralyzing illness, and a lot of pain and suffering have been caused over the years by vain attempts to do so. Whether or not a patient gets scoliosis depends upon the age of the patient at the onset of polio. If a patient were under 16, he'd get scoliosis at random; if he were over 16, he wouldn't. It's as simple as that. There is a little overlapping (14-17) in the nonrespiratory cases, but that only reflects natural variation in the ages at which the adolescent growth spurt occurs.

Severe Paralytic Poliomyelitis

| | <u>Scoliosis</u> | <u>No scoliosis (less than 50 curve in thoracolumbar spine)</u> |
|-------------------------------|------------------------|---|
| Respirator users (74) | 29 | 45 |
| Mean age at infection (years) | 8.7 | 27 |
| Age range at infection | 7 days to 16 years | 16 years to 49 years |
| Nonrespirator users (53) | 32 | 21 |
| Mean age at infection (years) | 9.4 | 31 |
| Age range at infection | 2 years to 17 years | 14 years to 55 years |
| Totals (127) | 61 | 66 |

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REACTOR: HEALTH-CARE PERSPECTIVE

Augusta Alba, M.D.

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Several solutions to provide increasingly independent living arrangements for the ventilator-dependent individual have been initiated at Goldwater. Intermediate care alternatives have included the "young adult ward" and placement of some patients in a skilled nursing facility. Other approaches have included halfway homes (transitional living), group residence (integrated living), living with families, or living independently at home utilizing vendorized community services.

In all of these arrangements, the role and relationship of a regional respiratory center must be defined. Innovative ways can be found to provide for the continued availability of medical care in relation to the resources in the community.

* * * * *

The Evolution of Intermediate Care

In our respiratory care unit, we had similar problems to those discussed by Dr. Spencer. We became overwhelmed with patients, and we could not treat any new ones. One way we were able to get around this was by establishing a young adult ward at the hospital. It turned out, for political and other reasons, that it finally had to be closed, but we got good experience from it. I was able to transfer about half of my patients, including Marilyn Saviola (who is attending this conference), to the young adult ward.

If we were going to start another such special ward in our long-term hospital, we would put it in the skilled nursing facility (SNF) rather than in the hospital proper because of the problem of payment. Third-party payers will not reimburse a hospital if the individual is in a vocational program or claims psychosocial needs as the reason for being in an institution. Third-party payers will accept charges for occupational therapy, physiotherapy, and speech therapy. These charges can be justified and reimbursed in skilled nursing facilities. Our adult ward concept and experience can be used for future planning, as a kind of halfway house, for leaving the respiratory center.

The Role of a Skilled Nursing Facility

The next thing we tried was our skilled nursing facility (SNF) where the cost in 1981 was approximately \$90 per day. [The cost in a respiratory rehabilitation unit is approximately \$175 per day. -- Ed.] However, we did not have enough staff to take care of all the respiratory patients there. In addition, it is much cheaper to provide a one-to-one ratio of care for a person in the home than in a skilled nursing facility where there are many other costs.

We can place but a few selected patients in our SNF, specifically those with tracheostomies who require minimal

suctioning. In the SNF, we use a respiratory alert card. If I have a patient there who is likely to have respiratory problems such as respiratory infection, the doctor on duty can simply look for directions in the front of the chart where the card is placed. In essence it says, "Please get him back to the hospital setting because he is really going to have a rough time unless he has the proper personnel to take care of him when he becomes ill." The alert could apply to something as minor as a cold because they cannot handle the mucus in a SNF.

Independent Living Arrangements for Respirator-Dependent People

The next step is to arrange housing in the community with family or alone. In New York City, one has to wait five to ten years to get an apartment, and rentals are very high. Fortunately, the federal government passed a law known as Section 8 Housing, which has been our lifesaver for getting patients back into the community. If they qualify for Section 8 Housing, they only have to pay 25% of their income for rent, the rest being paid by the government.

In addition, we were very fortunate on Roosevelt Island to have an experiment in independent living. City planners decided after many years of discussion to build housing on the island with federal monies. Already 2,500 families live on the island in what is called Island Town. Because Section 8 Housing funds were used, a certain number of apartments are reserved for the disabled. Between Bernard Cohler Hospital (another long-term hospital on the north end of the island) and ours, we were able to obtain 50 apartments. That means we have 25 apartments available to us. As someone leaves or dies, the apartment is given to another patient. About half the apartments are used by respiratory quadriplegics, including those who have had polio.

The Relationship Between Independent Living and the Respiratory Rehabilitation Center

For those living independently, Goldwater provides physiatrists for general medical care. Our people come back on a monthly basis to have their prescriptions filled. Also, a nurse practitioner from the hospital makes home visits and reports back to one of the physiatrists. Each physiatrist serves about five Island Town patients, in addition to duties in the hospital proper.

The Half-Way House - Transitional Living

Another service we have used was started by a farsighted couple, a registered nurse and an attendant. They decided to develop a group home for the physically disabled. No sooner had they opened when the man died of a cardiac ailment. The woman left in charge found there was just no financial remuneration in it, so she left. The City of New York did not appreciate that one person was handling this entire project, so the group home has since been run by other people. We have been able to send four quadriplegic patients through this halfway house. Some of them, after one or two years, want to leave and have their own apartments. Right now we have only one of that group still living at the halfway house.

The Group Residence - Integrated Living with Shared Services

The next thing we were able to do was to get our quadriplegic who can't go into the home into an existing group residence. There are apartment buildings for quadriplegics in New York City, but they have never taken respiratory quadriplegics.

We expect to have our first breakthrough this year. There is an apartment

building for quadriplegics in Erie, Pennsylvania. They accepted one of our quadriplegic patients when we gave them a real sales pitch for taking respiratory quadriplegics. My argument is that every quadriplegic is potentially a respiratory quadriplegic. By accepting one, the residence will understand the problems and be able to apply what has been learned from this person to the others. He was accepted, but this particular young man decided he would rather go to the Cheshire Home opened in New Jersey (9 Ridgedale Avenue, Florham Park 07932). He was the only respiratory person accepted among the 35 residents.

We have to develop laws, rules, and regulations on how a group residence for the physically disabled will be run, because there are no guidelines. Regulations exist for the mentally retarded and the psychiatric patient, but not for the physically disabled. The new Cheshire Home has had to open with nursing home status and regulations. However, it is run according to the original Cheshire Home concept. When talking to Audrey King from Ontario, I learned that there are 11 Cheshire Homes in Canada.

Independent Living at Home with Vendorized Community Services

The best that can happen is, of course, to have the individual go home with the family, but only about one-third or less of our patients can do so. The majority do not want to live with their families, because we have a good service in New York City. The New York Medicaid program will provide two 12-hour-a-day attendants or one 24-hour-a-day attendant.

As of last year, services in New York City are vendorized. The contract for the independent young adult who is living in the community has been given to Concepts of Independence for the Disabled, Inc. (CID). One can choose and train one's own attendant. CID will take care of all the paperwork, pay for compensation, dis-

ability, vacation, sick time, and make sure there is another attendant if your attendant is absent.

By talking to several of you, from Canada and the United States, I have learned that services are not this good elsewhere. They should be just as good, because, as Dr. Spencer has shown, giving supportive services in the community has been proven to pay for itself. The government's argument is that if you empty a bed and put a person in the community, you then fill the bed again, so you are spending more money. [If one thinks of this as a social issue, the person in the community returns to society far more than is taken out when he is a passive recipient of care and funds. -- Ed.]

Necessary Medical Care for Ventilator-Dependent People - New Directions for the Regional Center

I want to speak very briefly about medical care. At Goldwater, we bring patients back for what we call a one-day evaluation, and they are admitted into the hospital for that day. They are asked in advance about what they need, whether it be gynecological services, x-rays, dental, orthopedic, podiatric, etc. We try to do as much for them as possible, because community hospitals find it very difficult in busy outpatient departments to take care of the needs of a quadriplegic patient.

Wherever we can enlist the services of the acute general hospital, through their inpatient or outpatient services, we do. We do not want to be Mother Goose, providing everything to the extent that the patient does not try to find services locally. Where services do not exist, our inpatient and outpatient service will do the job. We still pick up the tab, with the hope that eventually localities will learn to provide total service for quadriplegics. I hope that the spinal injury clinics and centers developing throughout the country will recognize that they are not only for trauma of the spinal cord but for every

type of quadriplegic patient.

What I have been doing for the past few years is indoctrinating chest internists, pulmonologists, or respirologists. Respirologists are internists trained in the subspeciality of chest medicine. Although they have specialized in chest diseases, most of them know nothing about the neuromuscular diseases. In recent years, they have been pressed into service by the patients themselves demanding care. As a consequence, some of them are trying to learn more about respiratory disease.

Respiratory therapy services are also becoming involved. They are beginning to recognize that portable respirators are here to stay, both in the treatment of neuromuscular disease and intrinsic lung disease. This is a type of respiratory problem which they have not been routinely trained to care for. Allied health personnel can be the major source of

cost-effective, personal service for this kind of patient.

Our biggest problem is the acute care of the respiratory quadriplegic in the acute care hospital. We have the hardest problem obtaining integrated services in the University hospital, which is a voluntary hospital, and in the City hospital. Members of the chest service do not want the patient because they consider him a boarder. The adult emergency services does not consider him an adult emergency; urological, plastic, and orthopedic surgical services believe that their nursing staff is afraid of the patient. They can't take care of them, although we have offered to teach them what the small respirator is all about. The ICUs never have a bed for them. When it comes to surgical and diagnostic procedures that have to be done in the acute care hospital, we still have a long way to go.

CONSUMER PERSPECTIVE

Judy Heumann

Director, Center for Independent Living,
Berkeley, California

Contracted polio and is paraplegic

The approach to services needed for the disabled must be considered broadly, at a national, regional, and local level.

National level concerns include programs that generate research as well as the right to appropriate and uniform health care, attendant care, and equipment repair.

Regional level concerns include information collection and processing, technical device assessment and distribution, the education of health-care professionals and consumers. A regional hotline could have many uses, among them the coordination of information and services for both lay and professional people.

Local level concerns can be met by the independent living movement which provides demonstration models for delivery of services and for consumer advocacy. Its services include attendant care referral, housing placement assistance, and peer and family counseling. The services focus on functional needs and disregard the category of disability. Local independent living organizations have increased the political involvement of the disabled as they discover the commonality of their needs.

* * * * *

A Broader Perspective About Needed Services

The purpose of this discussion is to talk about regional service delivery. I

would like to broaden that topic a little bit, because I do not think we can talk about the issues of a region without looking, too, at the national and local levels.

The National Level of Needed Services

What we need in this country is a health-care program which guarantees that all of us have a right to receive health care. We no longer should have to worry about whether or not we can afford to see a doctor but be able to see a doctor or other health professional because we need to see one.

We no longer need to hear about New York having a good program, California having a good program, and one or two other isolated places having good attendant care programs. Attendant care should be a right for all who need attendant care in this country. We should no longer have to get into these discussions about isolated attendant care services. Without national attendant care, we have abysmal services in certain parts of the country, and people are moved from one place to another whether they want to be or not.

We should also look at needed services for equipment repair, for respiratory equipment, as well as braces, crutches, and wheelchairs. There needs to be a way of ensuring that there are places we can go for quick, efficient, cost-effective ways of maintaining equipment. If we do not have these services, everything else

we are talking about becomes reduced to a hit-and-miss approach to life, which is basically what I think exists right now. We live in the same country, and one person shouldn't be luckier than another because of the region in which he lives.

Another issue that is a national need is medical research. The government, in my opinion, has abrogated its responsibility by turning over to the voluntary sector the responsibility of defining major research goals and finding cures to such problems as cancer, heart disease, and polio. I really think that should be the responsibility of government. We are paying taxes to ensure that a significant amount of research is going on. I would like to see the National Institutes of Health be responsible for the vital issues concerning polio survivors.

To find out that Congressman Murphy received a letter from the March of Dimes saying that polio might be a virus that lies dormant and then activates itself, is not very reassuring. When I ask who is doing the research, I find out that nobody is. I think that these kinds of issues should be tracked down so that the appropriate governmental agencies are doing what needs to be done. It does not mean that the private sector shouldn't be involved, but it does mean it should be a collaborative working relationship, which I do not think is what is occurring now.

The Independent Living Movement - The Local Level of Service Delivery

I would like to talk about the Center for Independent Living (CIL) or the independent living movement. For now, I am skipping the region and looking at the independent living program as a local model of service delivery.

The Center for Independent Living has programs that are based in the local community. These programs have a limited impact because the services are provided within a certain geographical area. The Center was started in 1972. Since

then, there are about 150 to 160 programs of varying sizes, shapes, and configurations. The program we run in Berkeley, California, was started by disabled people who were not satisfied with the existing service delivery mechanisms. These were people living in either institutions or in institutionalized settings, but who could be living with a family. We thought that we had access to a lot of information and expertise and should be looking at what other movements were doing. This meant we began to act for ourselves.

The Independent Living Movement - Multiple Roles and Issues

One can look at the independent living programs as a service delivery model. But it is also an advocacy model. One of the most important aspects of the independent living facility is that we advocate on behalf of ourselves.

We have, in many cases, broad ideas about what needs to be done. Many of us have thought a lot about what the problems are and feel secure that our solutions to our problems are correct. We believe that we have the information and expertise with which to approach our needs. We can call on professionals to give us technical backup support. However, our programs for independent living facilities are relatively poorly funded. We have not had the money to effectively and efficiently accomplish what we believe we can.

The Independent Living Movement -Range of Services

The independent living programs provide attendant care referral services. The programs do not employ the attendant; they refer the attendant. Each disabled person can then freely hire and train his own attendant. We also provide housing placement assistance. In our programs, we modify homes, we see that people obtain Section 8 Housing, or we find out what other monies are available.

Our services are provided not to any single category of people but to a wide range of people. We serve people who are blind, deaf, mentally retarded, and physically disabled. This includes those with multiple sclerosis, polio, or cerebral palsy, in or out of wheelchairs. We have looked not at the label but at the functional needs of people. This has been a very important definition in the delivery of our services.

The CIL has increased the political involvement of disabled people. In many cases, for the first time, people with different disabilities have gotten together to learn about our differences and, more importantly, to learn about the similarities of our needs. We are beginning to band together to form a political movement, a civil rights movement for disabled people.

We conduct peer counseling. We bring disabled people together to work with other disabled people and to discuss problems and solutions to common problems.

We also involve the families -- parents, siblings, husbands, wives -- all those people who so frequently are not thought about. If family members are ignored, they can totally disrupt everything. It can happen that either the nondisabled person's life falls apart, or the disabled person's life falls apart, or everybody's lives fall apart.

We meet all of these needs with a mishmash of service delivery, like shopping malls where people can go to 20 or 30 different stores at the same location. People find this concept actually to be much more efficient. At an independent living program, one finds a whole range of services that previously one either could not get or could get only by going to many agencies. One finds people with all different kinds of disabilities working in these programs, people with information on technical aids and people who can design technical aids.

At CIL in Berkeley, we do not have a lot of money for such things as furniture. We designed a modern adaptation to the desk (raised up on bricks) and the telephone (extended with a gooseneck) to make them adaptable. Those things are not innovative to many of us, but in traditional organizations, people simply don't think of them. Such innovations as these allow us to begin job development, job counseling and placement, and employer education, with information about the most efficient ways to hire disabled people.

Why the Independent Living Center Must Have a Local Emphasis

These centers for independent living are local programs because there is only a certain amount of territory you can effectively serve. For example, when recruiting and employing an attendant, one must look at it practically. No one is getting rich being an attendant. They earn \$3 to \$5 per hour and are frequently students or part-time workers. If the centers are going to be cost effective, they must recruit locally and operate a network of centers.

Regional Service Delivery

After saturating a local target area with appropriate services, one can then consider the many needs that should be looked at regionally. The federal government has all kinds of regional divisions. If we are seriously going to examine the issue of regions, we need to define what a region is. We also need to answer the question of what we would be providing regionally and who would be served through a particular region. Regionally there are certain questions for people who are post-polio. But we also want to know how to impact as many people as possible.

I think regions should be utilized to collect ongoing data. In the case of polio, apparently no one has a lot of data. How many post-polio people are there? Where

are they? What are the differences among them? Which areas have more polio people than others? What kinds of technical aids and medical attention do they need? Who in the region has special knowledge or training that relates to the post-polio condition?

A regional program must develop a mechanism whereby one begins to collect and process quantitative information. If there are sufficient issues that need examining and enough people who need to be involved, it seems to be that this would make a regional program effective.

In England, there is a program called Technical Aids for Independence. There, one can see and touch lots of different aids and have professionals available to help determine which aid would be most effective for that individual. Regionally, we need to consider a similar program.

Also, a regional center could serve as a place where all different kinds of aids could be sent for study to determine which ones were most effective. If we were able to know what was needed on a regional basis, the region could become more effective as a source of supply and distribution, and there would more likely be funding to pay for this service.

A regional program should be utilized as a training center for medical professionals and consumers, not just in the area of polio, but in other areas as well. Then a regional program could provide and disseminate information, knowledge, and skills.

The training of professionals is very important. This includes doctors, nurses, paraprofessionals, occupational therapists, physical therapists, and disabled people joining professionals. Training professionals without disabled people is generally a futile exercise. Able-bodied people do not know what our needs are and, therefore, cannot be effectively trained unless they are working with us.

Several things could be done with a

telephone hotline at a regional level. In the case of polio, a regional hotline could provide information about needed resources and services. One could increase its effectiveness with a national ad campaign: "If you have polio and if you are having any problems -- which could range from back problems to breathing problems, to fatigue, to muscle degeneration -- call this number." I don't know where the number should go or if it should be hooked into a national health statistical program, but to some place where we could start identifying who the polio patients are, where we are, and what our needs are. That could be done regionally as part of a data collection system.

Another purpose of a hotline could be educational. On TV there is an advertisement, "If your baby has this rare disease, call this number." They can then hook you into what is going on with that disease all around the world. That should also exist for consumers and health professionals. If I go into a doctor's office and the doctor does not know anything about polio, he could find out from a regional information center. We need to coordinate information and services.

The Polio Crisis Today

Today I heard some people say that we cannot create a crisis like the polio one of the 1940s and 1950s. To a degree I think that is true. But I also believe that there is a crisis when we can sit down and discuss 20 people we knew who died in their thirties and forties for apparently no reason, except that they did not use the appropriate technology. Why? Because no one told them about it. Because people were afraid of using it. Because they had bad treatment from health professionals, which is bound to occur if doctors are not properly educated. If doctors don't know about polio and someone comes in with a respiratory problem, how can you expect them to be able to give the disabled person appropriate treatment?

A Call to Action

Polio survivors have always been innovative, creative, and radical. I think that has been to our credit. It is also equally important that post-polio people continue to be the population which acts as very strong advocates, not only on behalf of ourselves but on behalf of others with disabilities. We should realize that, as long as poor health care and poor service delivery are not corrected, society has to pay a high price.

It costs \$40,000 in California to keep somebody in a state hospital. I really can't discuss the issue of there not being enough money because I think there is more than enough money. The military budget in this country is going up, more and more people are becoming disabled, and as a result there is less money directed into the area of disability.

I do not believe there isn't money out there. I think it is an issue of government priorities. As long as we allow our government to set priorities which are not going to serve people, there will not be enough money. We are also talking about finding a way of making sure that the dollars that are spent are being spent effectively and efficiently. In my opinion, they are not.

The March of Dimes is a foundation

that was born because of us. Most people who contribute to the March of Dimes still believe that it is doing something for post-polio survivors. One of the things that should come out of this conference is that there ought to be a letter, a delegation, a meeting with the March of Dimes. They ought to be informed that we believe they have a greater responsibility to deal with issues concerning polio. I consider myself a living person; I am not dead. I am really sorry that the March of Dimes changed its priorities for whatever reasons. They have a responsibility, or they ought to let the public know they are not meeting the needs of post-polio persons, so we can begin setting up another organization.

Finally, we have to be outspoken advocates. That is the most important point to come out of this conference. We should maintain strong linkages among ourselves and stop being afraid of talking about what is going on with us -- from a very personal level to the very broad level of what is happening with disabled people around the country. If we do not take the responsibility for acting effectively as advocates, we have not only done ourselves a disservice, we have done a disservice to many other people who really need support and encouragement. They must know that it is their responsibility and their right to talk about their needs. Those needs should be met. We should not consider ourselves beggars any more.

REACTOR: CONSUMER PERSPECTIVE

Valerie Brew Parrish

Associate Director, Career Planning and Placement Center,
Southern Illinois University, Carbondale, Illinois

Contracted polio at age 5 and requires respiratory assistance

A personal experience with a modern life situation provides a realistic illustration of the unique needs and physical conditions of polio survivors. It is crucial that polio survivors, their friends and families, their care givers, and the organizations which serve them understand what these unique needs are.

* * * * *

A Personal Experience with Respiratory Polio

I contracted polio in 1956 when I was five years old. As I watched the slides showing the various types of respirators and iron lungs that have been developed over the years, I found myself reliving my own personal experience with the iron lung. The lung was safe and comforting, and I had convinced myself that I wanted to stay in it. Even as a child of only five, I was well aware that the lung was sustaining my life.

After a great deal of persuasion by hospital staff, I was slowly weaned from the iron lung to the rocking bed. I was terrified of giving up the security that the lung offered, and the hospital staff had quite a time getting me out of it even to try the rocking bed. I soon discovered that I loved the rocking bed, although it made my family dizzy to watch the constant motion of the bed moving up and down. I vividly recall one morning when a nurse said to me, "Valerie, if we can't get you out of the iron lung and off the rocking bed, you can expect to live the

rest of your life in a hospital." I quickly made up my mind to cooperate with the doctors and nurses. I was finally able to function without the respiratory aids that were once so vital to my existence.

An Active Career

As the years passed, the early stages of my polio experience began to fade in a distant corner of my mind. I grew up, obtained a Master's degree, and became employed at the Career Planning and Placement Center at Southern Illinois University as the Placement Specialist for handicapped students.

It is my responsibility to assist the students in finding suitable employment. I have traveled extensively throughout the United States, hopping on planes, hopping off planes, in order to present programs to employers on hiring the handicapped or to participate in some of the many consumer organizations that I am involved in. In my many associations with handicapped people, I knew relatively few people who had experienced polio respiratory problems and even fewer who had actually experienced using the iron lung.

A Flight of Terror

On July 11, 1980, I experienced one of the most unfortunate incidents of my entire life. Post-polio survivors, let me offer this word of caution. When the television or radio station advises its

audience to "fly the friendly skies," please beware. Airplanes can be hazardous to health and life of a former iron lung user!

On July 11, I boarded a small commercial plane that was to travel to Springfield, Illinois, departing from Carbondale at the Southern Illinois University airport. Carbondale is approximately 350 miles south of Chicago and about 200 miles from Springfield, my destination. The day was hot, and the temperature on the plane was about 140 degrees. The actual flight time to Springfield was about 2½ hours because we first flew to Cape Girardeau, Missouri, and then to St. Louis. I started having problems during the flight. I didn't know what in the world was happening to me. It felt as if my chest were about to explode; I could not get any air.

There was no flight attendant on the plane to assist passengers. When we landed in St. Louis, I still had enough strength in my legs to somehow get out of my seat and to go the pilots and tell them I was in trouble. I told them I needed oxygen and to please get me off the plane. Instead of heeding my advice, they laughed and said that they would try to fly the plane at a lower altitude so that it might be a little cooler. I did not have enough strength at the time to get myself off the plane. By the time we took off again from St. Louis to Springfield, I was really experiencing trouble and everyone on the plane knew it.

There were two ladies on the plane who tried to give me assistance. One was sitting in front of me and one was across the aisle. They began to fan me frantically in order that I might get some air. One of them tried to shove my head down in between my legs, which was the worst thing she could have done, but I did not have enough air in me to tell her to stop. I heard the one woman ask whether or not she should do CPR on me. Luckily I was able to somehow tell her that I was not having a heart attack -- I just couldn't breathe.

Finally after what seemed like an eternity, we reached the Springfield airport. I don't know how, but those two kind-hearted ladies carried me off the plane. The pilots had not radioed ahead for an ambulance. My fiancé, Rick Parrish, was meeting me at the airport. We had planned to go to dinner before he was to drop me off at the hotel for my meeting with a consumer group. Rick was appalled when he saw me being carried by two women. His fast action literally saved my life. He immediately called an ambulance and found someone at the airport to give me first aid. I nearly died. I couldn't breathe, and the first aid attendant told Rick I had no heartbeat or respiration. The oxygen began to revive me, and the ambulance whisked me away to the hospital. None of the doctors understood what to do for me. They simply administered oxygen and a few hours later released me. They said, "Okay, you can go home now."

A Waste of Potential

Rick took me home with him, and, as a result of this incident, I missed eight weeks of work. I am usually extremely healthy and a bit of a workaholic, and I became depressed at feeling so weak. I did not know what had happened to me. I was still having problems breathing. The only relief I could get was to put my face over the air conditioner vent. My legs, my strong legs that I use like most people use their hands, would not support me. I could no longer make a bed or do the things I was accustomed to doing. I wondered if I was ever going to be the person that I was before the ill-fated flight.

Thoughts of the iron lung came back to me. However, the doctors that I saw said they didn't know about iron lungs. I began to wonder if perhaps I might have to live in a hospital setting where they might provide the respiratory care I was requiring. I called my orthopedic doctor who is now in his eighties and asked him if I was going to be all right. He answered,

"You made it once, kid, and you are going to make it again."

And here I am. He said it was going to take a long time to recuperate, and it took almost a year. I was really afraid that I was not going to make it to my own wedding.

A Happy Conclusion

I returned to Chicago, where my family lives, to prepare for my wedding. I got in touch with Margaret Pfrommer who told me about Dr. Goldberg's interest in helping post-polio people with respiratory problems. I was so relieved to know that there are doctors who care enough to want to learn about the conditions of those individuals who have unusual medical difficulties. I realized I knew very little about my own condition and how imperative it is to have this type of information. I asked Dr. Goldberg if he

thought I would make it down the aisle on my wedding day. He said, "Don't worry, we will work something out."

As it turned out, I had a very cool day when I took my marriage vows. It was thundering and lightning, and I was the happiest bride anybody ever saw. In March of 1982, I will become a mother. [On February 17, 1982, a healthy baby girl, Tarra Bernice, 6 lb. 4 oz., was born to Valerie and Rick. -- Ed.] I feel as though I've come a long way.

We Must Make People Aware of Us

In summing up, what I want to get across is that it is extremely important for all of us to know as much as we can about polio so we can inform the doctors who may be treating us someday. The more information we have, the better we can serve ourselves and the doctors who treat us.

ORGANIZATIONAL PERSPECTIVE

André Dessertine

Magistrate, Creteil, France

Former President, World Veterans Association

President, ADEP (Association d'Entraide des Polios Handicapés)

Invited guest of the U.S. Congress, 1976

Recipient of the Legion of Honor for service
to the disabled community of France

Contracted polio, 1962, in Paris and is paraplegic

The French social system includes a social aid law which provides funding to meet the needs of the disabled and permits the development of service organizations like the Association d'Entraide des Polios Handicapés (ADEP). ADEP provides a wide variety of services to severely disabled people, including those who are ventilator-dependent, throughout the greater Paris region.

ADEP's requirements for independent living are medical security as indicated, life as independent as possible, and social integration as much as possible. Through a unique system of state funding, combined with intergroup cooperation, respirator-disabled people without families are able to participate in integrated, fully serviced, independent living centers.

The actual programs are: ADEP Assistance (a regional home ventilation program serving over 500 adults); ADEP Documentation (a registry of resources and information processing center); and Foyer d'ADEP (independent living center for adults who depend upon mechanical ventilation).

[Mr. Dessertine apologized for speaking in French. His commentary was translated by Dr. Goldberg as follows. -- Ed.]

I am going to explain our program and the situation that makes France different from the United States in the simplest way possible.

The French Social System

In France, there are many organizations which have created a number of interesting programs for handicapped people. We also have centralized and regulated ways of dealing with questions relating to the handicapped. This is due to a Social Security law that pays the costs of many of the services. There is also a Social Aid law which provides funding to meet other needs of the disabled, including housing, accessibility, etc. Because of these laws, our program, ADEP, can define and provide services to the population with severe disabilities, especially those with respiratory insufficiency.

* * * * *

The French Regional Approach

ADEP is a regional program. "Regional" has a special sense in France. Small communities, villages, or cities are grouped into larger units which make up a department, and then a region, which is defined politically. Our program deals with the City of Paris, the region called "Ile de France."

History of ADEP

The history of ADEP goes back to polio epidemics and the Hospital Raymond Poincaré in Garches, France. The original ADEP beneficiaries were the polio survivors living in that hospital. For them, in 1960, there was no solution except to remain in the hospital. Naturally, those polio survivors who were my comrades, my friends, wanted to get out of the hospital. They were preoccupied with the future. Together, we polio survivors created our program. We started with an analysis of our needs and desires.

ADEP's Basic Requirements

We determined our basic requirements to be:

1. Medical security. These people had been in the hospital for many years. Naturally, they had a great deal of fear. By dealing with medical security, we relieved their anxieties.
2. Life as independent as possible. To accomplish this, we needed to provide unique services for ventilator-dependent people.
3. Social integration. We wanted to integrate people as much as possible into the community.

ADEP Assistance - A Regional Home Ventilation Program

The best solution was to return home.

At home, one could be part of a family. But the family had to be willing to have the polio survivors home. For the people returning home, we created ADEP Assistance to provide and maintain equipment at home. The home ventilation program, which initially started for polio survivors, now serves many different kinds of people requiring ventilation at home, some having lung problems and some having muscular weakness problems. ADEP never interferes with medical intervention. Medical management is totally at the discretion of the primary physician or the regional respiratory center at Garches. ADEP simply provides the ventilator that has been prescribed and makes sure it is functioning.

But there was a remaining group of people -- polio survivors and others with severe neurologic motor disease -- who could not go home, and another solution had to be found. These people had to have a solution which also met our three requirements. We did a lot of thinking. We realized that we needed the documentation of other efforts so as not to waste time. This documentation would supplement our concepts for independent living.

ADEP Documentation - A Registry-Information Processing Center

We created ADEP Documentation for our purpose and for anyone else who would need information about available resources. Our documentation center in Paris contains all available information in any form relating to the full spectrum of issues concerning the disabled. Our documentation center receives information from many sources and many organizations in Europe. Our documentalists (in France, they are highly trained postgraduates) collect, classify, and process requests for information. Anyone or any group can request information for any reason. The relevant information will be provided in the form requested.

We now use the documentation center to answer a number of different types

of questions. For example, we can study the question of the legal rights of the disabled. As a result, ADEP became involved with legal intervention, advocating for the rights of the disabled. Other issues documented include accessibility of rental units, vacation sites, work places, transportation, etc.

At ADEP Documentation, we have consultants who are able to answer the questions asked of this documentation center. I am the legal counselor; we also have an urban architect and an engineer. A social worker deals with the problems of the Social Security and Social Aid laws.

All of the consultants are volunteers. The documentalists make sure that the classification of material and actual operation of the information service is provided. We work in liaison with other documentation services, some of which are involved with technical aids. [Another excellent documentation center in Paris is CNFLRH, 38 Blvd. Raspail, 75007 Paris, France, Mme de Castelline, Director. -- Ed.] Another center provides resources relating to issues dealing with children.

Foyer d'ADEP - Independent Living for Adults who Depend upon Mechanical Ventilation

At ADEP we have reflected upon the independent living needs of adults with respiratory insufficiency who cannot go home. We have talked to physicians, administrators, and consumers, and we have created two different independent living centers (at Montreuil in 1972 and at Evry in 1978). These independent living centers are integrated into existing apartment houses in the community to permit an exchange of living experiences among all who live there.

Each resident has a studio apartment, which includes a living room, kitchen, etc., so that other people can live there or visit as they like. This was a very satisfactory option for people who now

can rent their own apartments. They can live with whom they want, furnish their homes as they desire, and have available the shared services they need.

How Foyer d'ADEP Works - The ADEP Team and System

These apartments satisfy the Social Security and Social Aid legal requirements. To guarantee the Social Security funds, we have a staff that works with ADEP, Raymond Poincaré Hospital, and the government.

There are 15 respiratory insufficiency adults at foyer d'ADEP Evry. They are the medical responsibility of the specialists at Raymond Poincaré, who come once a week to visit them. The Chief of Staff there has the ultimate medical authority.

The health-care team includes one charge nurse, three assistant nurses, and a number of less sophisticated care givers. These care givers run the entire operation. During the morning, more people are working to meet the increased physical activity requirements at that time. In addition to physical services, any indicated medical services are provided. We also have a physical-respiratory therapist and an occupational therapist.

Each room has piped in compressed air and oxygen. There is a backup generator system to provide electricity in case of electrical failure in the village. There also is backup hand ventilation capability in each room.

Each resident has his own ventilator (serviced by ADEP Assistance). There is a very safe "call system" for both routine and emergency assistance. Each resident has more than one way in which to call. Also, each room has an individual environmental-telephone control system which is activated by hand or "sip-and-puff." Each resident has an electrical wheelchair which permits total independence and mobility around the building and the

village.

The apartments in Evry, one of the "new cities" of France, permits those who have free time (meaning autonomy from the respiratory aid) to leave their apartments alone to do anything they desire in this totally self-contained city. If they have no free time, they are accompanied. Many social activities are organized for the entire independent living facility by a social organizer in addition to those activities available in the city. Foyer d'ADEP has two vehicles with chauffeurs at the disposal of the independent living center, a small minibus which can take two people, and a little larger one that can take five or six people.

Foyer d'ADEP was planned to permit the greatest possible integration among all the residents of the City of Evry. The apartments at Evry, a total of 27, 15 for the respiratory disabled and 12 for the nonrespiratory disabled, provide a permanent solution for those who have no home and are an intermediate step for those who need the transitional phase. It must be clearly understood that these individuals cannot live entirely alone. The alternative would be hospitalization. [Among the residents, a group of highly motivated adults plan a small self-management arrangement, "un autre regard," an alternative solution. -- Ed.]

ADEP Assistance - Monthly Costs for Home Ventilation

| <u>Service</u> | <u>Monthly cost</u> |
|-------------------------------|---------------------|
| Ventilation | \$ 97 |
| Maintenance | 47 |
| Administration/Social Service | <u>16</u> |
| Total | \$160 |

SESSION V

**PREMATURE AGING PROBLEMS
OF POLIO SURVIVORS**

OPENING REMARKS

Allen I. Goldberg, M.D.

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Department of Anesthesia,
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Assistant Professor of Anesthesia and Pediatrics,
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The third day of our working conference will be devoted to answering the questions you have raised. In earlier sessions, we have focused on past experience with polio and on the present-day issues, namely, defining a health-care crisis and searching for technological and organizational approaches to meet current needs. Now we will focus on the status of the polio survivor and try to

answer the question, "Is there a post-polio aging problem?"

We have invited two experts to define and analyze this question. You, too, will have an opportunity to participate in trying to answer it. Your written questions will be directed to a panel of six additional experts who will present their ideas as well as answer your questions.

DEFINE THE ISSUE

Frederick M. Maynard, M.D.

Assistant Professor of Physical Medicine and Rehabilitation,
University of Michigan, Ann Arbor, Michigan

Post-polio aging problems are characterized by slow accelerations of the normal aging process. The neuromuscular issues of "post-polio amyotrophy" are illuminated by the results of recent electrodiagnostic studies. A decrease occurs in the normal number of nerves that innervate a given muscle, while some nerves compensate by an "expanded territory." The clinical manifestations are a decline in muscle strength and endurance as well as fasciculations (twitching). This is a very slow progressing problem, and it is not inevitable.

The causes of post-polio amyotrophy include normal aging superimposed on previous weaknesses. These weaknesses may result from overwork. There is a confusing relationship with ALS. Further research is needed to clarify the etiology of the condition.

The management of post-polio amyotrophy includes an appropriate exercise program, general health measures, prevention of secondary complications of weakness, consideration of life style changes, weight loss, and pulmonary evaluation.

The musculoskeletal problems that accompany post-polio aging include osteoarthritis, tendonitis, bursitis, and nerve compression syndrome. Inactivity may facilitate osteoporosis, phlebitis, deep vein thrombosis, and pulmonary problems.

The psychological aspects involve a constant reevaluation of priorities and life stresses, the need to make unwanted life style changes or further equipment

adaptations, and the threat of change to a more restricted and dependent life style.

* * * * *

To define the problem of aging in the post-polio person, I must begin by saying that all the problems of normal aging are going to apply to the post-polio person as well. I will try to focus my remarks on what are special aging problems in post-polio people, and I will tell you from the outset that they are very difficult to determine.

As a general statement, it appears there is some acceleration of several of the normal problems of aging. With advancing years, there is a decline in the reserve capacities of many parts of the body, such as cardiovascular function, kidney function, visual acuity, and hearing. These declines can be plotted on curves which show a fall-off in their abilities beginning in the third and fourth decades. When we look at the problems of the post-polio person and what is special about aging, we have to start by focusing on those functions which decline at an accelerated rate.

Neuromuscular Issues - Post-Polio Amyotrophy

Let us begin with neuromuscular function. Polio is an infectious disease caused by a virus that primarily affects what is called the anterior horn cell. These are the nerve cell bodies located in the spinal cord which run from that location out through the peripheral nerves of

the body to innervate muscles and make them contract. Thus, polio is a disease of the motor unit and the neuromuscular system.

It has been commonly held that once this viral infection happens, either a certain population of these injured anterior horn cells recover or they do not. The person then adapts to what he has left functioning in his neuromuscular system. While certain complications may develop in the process of recovery, a residual degree of muscle weakness is thought to be the end stage of the disease process. What has become increasingly evident through the years, particularly to people who have been involved with polio patients for a long time, is that a unique problem occurs in these nerve cell bodies later on which relates to the aging process.

The first issue we have to face is what terminology we use for this problem and what we mean by it. I prefer the name post-polio amyotrophy, amyotrophy being a general term for loss of function of anterior horn cells resulting in muscle atrophy and weakness.

Electrodiagnostic Studies - The "Expanded Territory"

One of the ways that physicians have to study the function of these anterior horn cells on a physiological basis is called an electromyographic examination. This study was available during the fifties when the polio epidemics happened, but it was not widely used because it was not necessary in the diagnosis of acute polio. There were plenty of other methods to tell if a person had polio. This test involves studying the electrical activity of muscle fibers when a muscle is contracting and at rest.

We learned by electromyography in patients who have had polio that there has been a decrease in the number of nerves that innervate a given muscle, since some anterior horn cells previously reaching

that muscle have died. The nerves that remain have gone through a process of sprouting so that some of the muscle fibers which originally lost their nerve supply were reinnervated by the remaining nerves which survived. The result is that one nerve cell now goes to as many as one and a half to three times as many muscle fibers as it would have normally gone to before a person had the polio infection. This is called an "expanded territory" of an anterior horn cell.

On an electromyographic examination, one sees a very large amplitude of electrical potentials, reflecting that many more muscle fibers are firing or contracting as a result of an action potential in one anterior horn cell. These units also have a complex wave form and are long in duration.

Dr. Ernest Johnson, one of the country's leading authorities in electrodiagnostic studies, related to me some research recently completed in his laboratory. He performed standard electrodiagnostic studies in post-polio people and confirmed the expected findings of complex, large amplitude motor unit potentials and a decrease in overall number of motor units. He then went on to do "single fiber" electrodiagnostic studies, a technique of looking closely at individual muscle fibers' electrical characteristics. He did these studies in post-polio people and in otherwise healthy people over age 80. These very old individuals clearly could be expected to have the normal problems of aging. He found the same abnormalities in both populations, i.e., expanded territories of motor units and an increased jitter, both characteristic findings of anterior horn cell degeneration.

The Clinical Picture of Post-Polio Amyotrophy

What does all of this mean to the person who has had polio? What are the symptoms of post-polio amyotrophy? The symptoms are probably familiar to most

of you who have had polio. They are a decline in muscle strength and endurance. I think it is particularly the decrease in endurance that is most troublesome, at least judging by the letters I have received in the last six months as a result of Alice Mailhot's article in the 1980 Rehabilitation Gazette which highlighted this problem. This process of decline in strength and endurance can happen both in muscles, which had a clear residual weakness as a result of the original polio infection, as well as in the limbs and the muscles, which previously had been thought to be unaffected. It seems to be more common in people who had polio when less than five years old. It can begin anywhere from as early as five to ten years after the onset of the original polio infection to as late as 60 years. The average time before people start clearly noticing that their strength is no longer what it used to be is between 30 to 40 years after the original polio infection.

For example, a post-polio person may have learned to rely on one normal or less involved leg for a great deal of activity and strength to compensate for a weakened limb on the opposite side. This person then may gradually notice that the "normal" leg can no longer perform at this higher level of work. The normal leg may buckle or collapse after one or two blocks of walking, whereas previously it would carry the person a mile or more. This declining strength causes many secondary problems, particularly falls, tiredness, aches and pains in the muscles, or difficulty climbing stairs and surmounting curbs.

Another symptom observed by post-polio persons who are developing this problem is fasciculation (muscle twitching). Fasciculations do happen in normal muscles, particularly when a person is fatigued and overtired. Caffeine and other stimulants can also enhance fasciculations in normal people. In post-polio persons, fasciculations are seen more frequently, particularly when post-polio amyotrophy is developing.

I want to emphasize that the time course for weakness developing in post-polio amyotrophy is usually very slow. That is to say, once a person has clearly been identified as having this problem, it is likely to be many, many years before there is going to be a complete paralysis or a major loss in muscle strength. I must also admit there is tremendous variability in how fast the disease progresses, but for the most part it is slow. Of course, time is relative, and you and I may not agree on how long "slow" is. In this case, slow means the progression of symptoms over years.

Another point I want to make is that post-polio amyotrophy is not something inevitable for all people who have a history of polio. There is no study that looks at how many post-polio people really experience this problem. I don't want people to leave this room saying, "Poor me, I have nothing to look forward to but getting weaker in my old age." While this problem will not happen to all of you, I think you all need to know that, if you do experience increasing weakness, there is a good possibility that this is what is going on.

The Theoretical Causes of Post-Polio Amyotrophy

There are three major theories that attempt to give explanations as to what is causing this problem.

The first theory is that we are seeing normal aging superimposed on somebody who has previous muscle weakness. For example, let's say that a person had polio and, out of a normal 100 anterior horn cells or motor units in an arm, 50% of them were involved by the polio virus and died. The strength that remains from the other 50 motor units may have left the extremity appearing normal, especially after the first six months to a year following recovery from acute polio when the surviving nerve cells have expanded their territories and picked up more muscle fibers. Perhaps this person could

not throw a baseball or football as far as his peers, but he could certainly do everything in normal daily activity and did not think of his arm as weak, particularly when compared to his other arm that had almost no muscles working in it.

What happens with aging is a gradual loss of these anterior horn cells in a person who has never had polio or other problems. This usually begins to take place in their fifties and sixties and accelerates in their seventies and eighties. For the sake of discussion, let's assume there is a loss of approximately 5% to 10% of anterior horn cells occurring every year after the sixth decade. If you lose 10% of the original 50 anterior horn cells, you will clearly cross the threshold of noticing that the arm is not as strong as it used to be, and you will have problems in using the arm for normal daily activities. Thus, in the theory that explains the whole problem as a result of aging superimposed on previous residual nerve cells damaged from polio, it is a decrease in the number of reserve anterior horn cells that produces symptoms.

The second major theory, which is not mutually exclusive from the first, has to do with overuse. We clearly know, and I think Dr. Bennett and others have clearly demonstrated, that muscles weakened by polio are particularly sensitive to overwork weakness. Extreme overwork may also precipitate weakness in normal muscles. If normal individuals push themselves to the point of exhaustion, they too will experience transient weakness; if they push even further, they may even permanently damage their muscles.

In a post-polio person, the point where muscles are damaged from overuse is reached more quickly. This is why, in general, exercise is not really effective for overcoming the problem of progressive weakness. Any muscle that has lost part of its normal nerve supply is particularly sensitive to overwork weakness. The theory is that the remaining nerve cells going to an expanded number of muscle fibers have increased metabolic

demands; with extreme activity they cannot keep up with these demands and are damaged.

Another aspect of overuse relates to the normal rotation of firing nerve cells when we perform an activity. An example may help to illustrate this. If I have 100 nerve cells in my extremity and I do a nonstrenuous activity, I fire only five of these 100 nerve cells at any one time. One group of five rotates and is immediately followed by a different group of five until half of the nerve cells have reached that muscle. If I perform a strenuous activity with the muscle, 15 or 20 firing cells begin rotating among the whole 100. No one individual nerve cell body is firing continuously. Now, if I have half as many nerve cells to begin with and they are going to twice as many muscle fibers, you can see that the normal rotation is among fewer cells. Thus, with maximum effort there will be a larger strain from more rapid firing and greater metabolic demands on any one nerve cell body. Extreme exercise of individual muscles does seem to have the potential to result in a permanent or lasting residual weakness.

Another way of looking at this problem is as a vicious cycle that combines overwork with aging and the post-polio loss of motor nerve cells. If there are fewer cells to begin with and you call upon them to do more work than they are physiologically made to do, then you are going to see nerve cell exhaustion and nerve death. This leaves you with more residual weakness, and you are going to have to stress what is left twice as hard. This becomes a vicious cycle.

Some people have hypothesized that post-polio survivors notice this progressive weakness in extremities, which previously had not been thought to be involved, because they have been calling on the relatively normal muscles to do more work for many years. After 20, 30, or 40 years of doing an increased amount of work, "normal" limb muscles are beginning to wear out or show aging changes

faster or at a younger age than in a person who has two entirely normal limbs.

The third theory, which is the one I think has really caused a lot of confusion in the medical profession, has to do with the similarity of post-polio amyotrophy with motor neuron disease, also known as amyotrophic lateral sclerosis, or "Lou Gehrig's disease." This, too, is a disease for which there is still no scientific explanation for its developing in certain people. Motor neuron disease is not clearly related to a virus, to a toxin, or to metabolic abnormalities that we know how to explain. It is associated with a rapid loss of anterior horn cells and a very rapid progression of weakness. By rapid, I mean that usually within a period of one to four years a person will be unable to walk or will die from respiratory complications or from swallowing difficulty that leads to aspiration. This is, of course, a very frightening disease.

The confusion between post-polio amyotrophy and ALS occurs because both diseases affect the motor neurons, the anterior horn cells, and they both tend to begin in later life. Both of them affect men more than women. Some research has actually shown that there are subtypes of anterior horn cells characterized by anterior horn cell subtype antigen characteristics. This research suggests that people who develop polio, as well as people with ALS, have a higher than normal proportion of a particular type of cellular subtype antigen. This has led to the theory that there is a hereditary predisposition toward diseases which affect the anterior horn cells, and that genetically some people who are predisposed to severe infections with the polio virus may also be predisposed to whatever causes ALS.

There does seem to be an increased incidence of what we would more clearly identify as ALS in people who have had a past history of polio. However, with the many similarities between ALS and post-polio amyotrophy, it can be very difficult to tell which disease may be producing

weakness in a post-polio person. Two things are helpful in distinguishing the two. One is how fast the weakness comes on; the second is that people with ALS usually have involvement of the cortico-spinal tracts, bundles of nerve fibers which connect the brain with the anterior horn cells and trigger them to fire. Involvement of these nerve fiber tracts produces spasticity and other signs of nervous system disease besides anterior horn cell disease.

There appears to be a continuum in the speed of the onset of weakness in post-polio persons ranging from those whose weakness is slowly apparent and mild, representing typical post-polio amyotrophy, to those whose weakness appears rapidly and is severe, suggesting the coincidental appearance of ALS in a post-polio person. What is most reassuring is that a proportionately much, much smaller number of post-polio persons develop this rapidly progressive type of problem. Since there is no clear way to tell these two problems apart when they first begin, I think if any post-polio person notices mild increasing weakness, he should assume it is the slowly progressive type. Physician evaluation and discussion are certainly called for when the weakness begins to interfere with critical daily functioning.

In summarizing these theories, I think most people believe that post-polio amyotrophy is a metabolic abnormality of the anterior horn cells that survived the original polio infection. Because of the altered metabolism, these cells do not live as long as usual and begin dying off with age, causing an acceleration of the normal aging process. Overuse and over-activity probably contribute to the metabolic abnormality and accelerate cell death.

A Call for Further Research

There are other factors which I believe need to be studied with further research. One is the relationship to

carbohydrate metabolism. People with ALS show some alterations in carbohydrate metabolism but not clearly diabetes mellitus. Adult onset diabetes mellitus appears to be a slowly progressive abnormality of carbohydrate metabolism associated with aging. Another possible etiologic factor is hypoxia, a decrease in cellular oxygen. We know that long periods of low oxygen, such as occasionally are seen in normal people who have a cardiac arrest leading to generalized low blood oxygen, may show selective damage or death of anterior horn cells. One can hypothesize that the effects of prolonged low blood oxygen on anterior horn cells of post-polio persons, cells which are already metabolically borderline, may be another factor.

A third factor to consider in research is toxin exposure. It is possible that low levels of lead, or low levels of other chemicals that are toxic to the nervous system, may have deleterious effects on anterior horn cells that have previously been damaged by polio, although they are not high enough to damage normal anterior horn cells.

Much investigation is needed to explain the loss of anterior horn cells with normal aging. Post-polio persons are an excellent group for the study of this phenomenon. They are like a laboratory group of people who are aging more quickly, in their forties and fifties, rather than in their eighties and nineties. This provides an opportunity to learn more about normal aging.

Management of Post-Polio Amyotrophy

I want next to speak about treatment. The first thing everyone thinks about in preventing weakness is exercise. It is important to have enough exercise, enough to prevent disuse atrophy, but not enough to produce overuse damage. The best guideline here is a feeling of exhaustion. If a period of activity or exercise is followed by a clear increase of weakness or decline in strength, then too much has

been done. People need to learn to do their own pacing and become sensitive and respectful of their body's signals. I mentioned before that patients with a past history of polio have never clearly been shown to respond to an exercise program of increasing weights. A vigorous progressive resistance exercise program is clearly something to avoid.

A second aspect of treatment is general health measures. Keep yourself in general good health by following proper diets, treating hypertension or heart disease, and maintaining an optimum respiratory situation. These general health measures can only help prevent the problem of post-polio amyotrophy.

Third, it is important to prevent the secondary complications of weakness, particularly falls. If you are falling, let's figure out what we can do to prevent these falls. Let's analyze the falls. Using braces or crutches, or maybe going to a wheelchair for long-distance travel or when you are fatigued, can often prevent the devastating results of a fall. If there is joint instability that is aggravated by increased weakness, let's adapt to that by appropriate splints, braces, or other adaptive equipment.

The next part of treatment is to consider life style changes. Perhaps a change of jobs, a change in the usual method of transportation, a change in hobbies, or a change in degree of attendant care or help should be considered in order to prevent further weakness or future injury.

Another problem is avoiding weight gain. It stands to reason that if a person gains weight there will be more demands for strength on his muscles. Greater work loads on weakened muscles are more likely to lead to overuse weakness.

Lastly, I would mention the importance of routine reevaluation of the pulmonary status of any post-polio person with a history of pulmonary problems.

Musculoskeletal Issues in Post-Polio Aging

A second major category of post-polio aging problems can be labeled musculoskeletal problems. These are problems that also occur in the general population, but people who are weakened, who have residual joint deformities, who are putting abnormal stresses and forces on their joints and ligaments are going to be predisposed to having more of these problems. Osteoarthritis, which is a wearing out or degenerative arthritis of the cartilage and joints, is more likely to happen in post-polio people. Again, the particular pattern of muscle weakness and a person's activity will influence which joints are most involved.

I had a memorable patient a few years back who developed such severe degenerative osteoarthritis of her finger joints that she could no longer push her wheelchair. She was an artist, and she desperately needed to use her hands. She decided to use an electric wheelchair so she did not have to grab onto her wheelchair rims. She saved the strength in her hands for her painting.

Another related problem is tendonitis and bursitis. The abnormal forces that people with weak muscles put on their tendons, particularly when they strain to do an activity, are going to predispose them to inflammatory changes in these tendons and their surrounding bursas. While there are many effective treatments for tendonitis and bursitis, a close analysis of what a person is doing in his normal daily activity is of utmost importance when the problem becomes chronic or recurrent. This aspect of treatment is often ignored or passed over quickly by both health-care professionals and patients alike.

The next problem I would mention is nerve compression syndromes. I heard some people last night describing symptoms that were very suggestive of nerve compression syndromes, such as the carpal tunnel syndrome, which produces numbness and tingling in the hands. With

joint deformities and/or abnormal uses of weak muscles, compression of nerves can develop, particularly in the arm, wrist, hand, and foot. Symptoms are usually numbness, tingling, and pain, often aggravated by a prolonged position or a repetitive activity. Indeed all the normal problems of the musculoskeletal system and nervous system that happen to normal people can happen to post-polio people. Another example is neck arthritis, which may be aggravated by looking up at people from a low sitting position in a wheelchair. Neck osteoarthritis can lead to nerve damage and secondary weakness in the hands. Evaluation would be needed to differentiate it from post-polio amyotrophy weakness involving the hands.

The Problem of Inactivity with Post-Polio Aging

Lastly, I mention the problem of inactivity. I would hope that post-polio persons are not inactive, but some with severe residual weakness must be. These people are going to suffer from problems of osteoporosis, or brittle bones, which fracture easily from minimum trauma. Other problems associated with inactivity include circulatory problems such as phlebitis and deep vein thrombosis, and blood clots in the veins of the legs. Pulmonary problems like pneumonia are also frequent with prolonged inactivity.

Psychological Issues in Post-Polio Aging

One further problem of aging that is of great importance is the psychological one. Again, this is a crucial subject about which we know very little. Today's life styles often include tremendous time and achievement pressures. When increasing weakness or decreasing reserves of muscle strength occur with aging, we all have to reanalyze priorities and pressures constantly. It is very difficult to give up activities we previously enjoyed because we feel we no longer have enough time for them when they begin to take longer. Taking time to rest may be the real

answer for many post-polio people who have this slowly progressive weakness. A nap during the daytime, working a shorter day, or taking longer vacations may all be excellent therapies.

A second psychological aspect for post-polio survivors is coming to terms with slowing down, making further life style changes, or equipment adaptations that signify weakness and are experienced as a defeat. If a person who has been struggling to keep on his feet for years is going to begin using a wheelchair, it will take a great deal of emotional strength to give up walking as the primary means of mobility. This may particularly be true for a person who has gone through a great deal of struggle and therapy 30 or 40 years ago in order to get on his feet after acute polio. Giving up a previously fought-for activity is a tremendous psychological hurdle. It is probably the most difficult part of adapting to a lesser level of functioning.

Alice Mailhot asked, "Do the virtuous fade first?" [1980 Rehabilitation Gazette, Vol XXIII, p 6. -- Ed.] I thought that was an interesting idea about the people who struggled the hardest to compensate with their weak muscles to look normal again and remain as active as possible. Perhaps they were predisposing themselves to this syndrome of post-polio amyotrophy more quickly.

A third psychological factor is the threat of change to a more restricted and dependent life style. For a post-polio person, this may be something he has struggled years to avoid and now is going to have to face all over again. This is a tremendous challenge and opportunity for people with post-polio to teach the rest of us, the so-called normal aging population, about what it is like to look forward to life and to be active in life in spite of physical impairments and limitations. People need to know that just because one loses physical capacities and has to adapt to increasing disability, whether from age, disease, or injury, it does not mean the end of all the things that are

important in life. You post-polios have fought this battle before. I think you will have tremendous ability to face the problem of declining function again, particularly if it occurs gradually. You may have an advantage over people who were totally normal until they were 60 or 70, and then developed some type of disability that suddenly left them with a decline of function. I think you have much to teach us about these psychological problems of aging.

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ANALYZE THE ISSUE

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Since it was established by Franklin D. Roosevelt in 1927, the Roosevelt-Warm Springs Center has had a long history of concern for people who have had polio. Many former patients keep in touch with original staff members who are still at the Center.

When the staff became aware that younger polio survivors were experiencing signs of early aging, a survey was sent, arbitrarily, to those survivors in Warm Springs in 1952. The preliminary results of the questionnaire are presented with additional input from survivors interviewed about post-polio aging on an NBC television program.

Of note were (1) a minor incidence of respiratory problems; (2) a considerable amount of high level independent activity and full employment despite permanent disability; (3) increased weakness, loss of endurance and unique pain in younger people; and (4) no real increase in health problems associated with the normal aging process.

* * * * *

Roosevelt-Warm Springs and Polio

Warm Springs has been associated with polio since the foundation was established by Franklin D. Roosevelt back in 1927. We still have some of the personnel who were there during the critical years of the fifties. Members of the staff all believe that they have benefited greatly from having the privilege of treating polio patients. They also feel that they learned

the real dynamics of muscle function and innervation from polio patients in a way they never would have by working with other people. We are now a full rehabilitation center, but we still follow a number of polio patients who have been coming to us for quite a long time.

An Awareness of a Post-Polio Aging Issue at Warm Springs

About three or four years ago, we became very much aware that the polio patients were having more trouble. Although we had recognized aging as a problem in all of us, certainly it is to be expected even more in the polio patient. But we were puzzled that some of our younger patients in their late twenties or early thirties were presenting problems of the same sort as those much older.

The Roosevelt-Warm Springs Questionnaire

We decided that we would try to see if there was a problem, or if the patients we were seeing were a small group that was not representative of the polio population as a whole. We tried to come up with a questionnaire that would not present leading questions or frighten anyone. Nor did we want to put any thoughts into anyone's head. As a result, the questionnaire is very inadequate, but we had reasons for making it that way. We decided that the best way to get a true sample was to select people from one of the peak years of polio and try to determine what

had happened to them since then.

We sent the questionnaire to patients who were in Warm Springs in 1952. What I have is a compilation of results from our 1952 patient questionnaire and from several other patients who contacted Warm Springs as a result of a television statement about a year and a half ago. They were also seeking some answers. We realize the results are skewed due to inadequate sampling. I am sure the people who contacted us were those who were having trouble. We believe we do not have an adequate sample or a complete questionnaire.

The Preliminary Results of the Roosevelt-Warm Springs Survey

Sex Distribution. Twice the number of females to males responded to the questionnaire. We are not sure that was the ratio of polio incidence; rather, we believe that females were more likely to take the time to answer the questionnaire. We also thought that they probably were more likely to be watching television at the time the polio segment was shown. But I do not know whether even that is a true assumption.

Age Distribution. The total number responding was just over 400. The age range of the respondents was between 27 and 84, with 154 (38%) below the age of 40. A number of fairly young people responded.

The age of onset of polio ranged from five weeks to 43 years; the age since onset was anywhere from one year to 74 years. The average age since onset was 41; the most frequently reported length of time since onset was 31 years. One person had polio the year prior; one nine years prior, and one 19 years prior. All of the rest had polio more than 20 years prior.

Incidence of Permanent Disability. Three hundred eighty (94%) had some permanent disability from the initial

attack. The lower extremities were the most commonly affected and the left lower extremity more than the right.

Incidence of Respiratory Problems. To try to get some idea of how many were having respiratory problems, we combined respiratory, throat, and general areas. We did not ask, "Are you having respiratory problems?" We deliberately avoided "pointed questions" in the questionnaire.

A relatively small number said that they were having respiratory difficulties. I am sure there were many with minor problems they did not mention on a questionnaire, but we were impressed that the respiratory problems were not major among the group who replied. [The symptoms of respiratory insufficiency -- fatigue, weakness, lowered level of alertness, and activity -- due to borderline oxygen delivery to or carbon dioxide removal from cells, may not be considered as "respiratory" in this survey. -- Ed.]

Incidence of Independence. Responding to questions related to independence of movement, 181 (45%) said they required bracing, and 380 (94%) said they were totally independent in self-care. That is something that the polio population should be extremely proud of. We have been impressed over and over that people with an unbelievable amount of weakness still are able to do what they need to for themselves.

The polio patient is able to use the muscles he has with much more efficiency than are people with almost any other diagnosis. We are just amazed at the persistence and the ability to perform, when ordinarily we would say, "You can't do that."

Incidence of Employment. The number of respondents independently employed was a surprising 341 (85%). Now, here again, we cheated a little bit. We did not phrase the question rigidly, and we included in the "employed" group those who noted on the questionnaire that they did not work but stayed home and took

care of the children and the house. Those of us who have had that job realize that it is work!

Level of Muscular Activity. To ascertain the level of muscular activity, we tried to find out how many were engaged in an active exercise program. As Dr. Maynard said, we do not usually recommend to polio patients that they lift weights or become cross-country joggers. We do encourage them to use their muscles and keep them in peak condition, but without overdoing it. We found that only 37% of the respondents were engaged in some sort of formal exercise program, mostly jogging, walking, or swimming.

Muscle Strength, Endurance, and Pain. The next question which asked about muscle strength was really the one we were most interested in: 84% of the respondents said that they were experiencing a recent change characterized by increased weakness and loss of endurance. Only two reported that they had improved. The rest had lost functional abilities. Many wrote full pages, and several had four- and five-page letters accompanying the questionnaire, telling us that we did not ask enough questions. So we did get a lot of extra information.

Another thing that puzzled us, and I do not think it is explained adequately in the theories, is that a fair number of people, many of them younger, have complained to us of a pain that is not really associated with muscle use, joint strain, or anything of that nature. They describe it as a deep ache. Several have volunteered the comment that it's the same feeling as when they had polio. I do not think the pain is related to muscle use. Along with the pain is the inability to sleep.

I do not think that we have the whole picture; at this point it is something we do not know how to explain, but we do need to investigate. I think it is a different type of problem from fatigue and overuse.

Surprisingly, those who had polio before the 1950s apparently missed this to a large extent. The ones in their sixties and seventies do not complain of this type of pain, only the young people.

Incidence of Associated Health Problems. We were also interested in the questionnaire finding about associated health problems. A lot of people asked whether they are more likely than most people to have hypertension or heart trouble. Without specifying, we asked if there were any other health problems. We wanted the patients to write down what they considered a health problem, so we simply asked, "Do you have any other health problems?" Forty-eight (12%) reported hypertension. Thirty-nine were over the age of 40 when most of us may have a little problem anyway.

Pulmonary problems were reported by 35 persons (9%). These were not the respiratory problems that accompany polio, rather they were things like emphysema and asthma. Twenty-four of the 35 were over age 40.

Forty-nine persons (12%) reported that they had arthritis, only one of which was rheumatoid. I know that Dr. Bennett and a few others have said that you never see a polio patient who has rheumatoid arthritis. So I thought that was an interesting finding, because actually very few post-polio patients have rheumatoid arthritis, although as Dr. Maynard said, quite a number have traumatic arthritis from joint trauma.

What Ever Happened to the Polio Patient?

In answer to the question, "What ever happened to the polio patient?" I would like to say that he is here, and as far as we are concerned, doing remarkably well. But polio survivors are having trouble, and they need our help. We really are very proud of you, and we think your problems deserve attention.

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SOLVE THE ISSUE

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Useful, practical suggestions and information are offered post-polio people who may have difficulty with any number of conditions. Those with quadriplegia are advised on how to obtain successful venipuncture, avoid fungus infections, cope with gastric dilation and constipation, and alleviate the pain of arthritis. Advice is given on how to assume a proper sleeping position, how to perform positive pressure (frog) breathing, the importance of obtaining vaccination for influenza and common pneumonia, how to handle tracheostomy cuffs, and how to prevent renal stones.

* * * * *

Tips for Successful Venipuncture in Quadriplegics

For those of you who are quadriplegic and still have some veins, one thing you can do is inform the doctors in the hospital that, if they are having a really difficult time finding a vein, they can contact the Physical Therapy Department and request some hotpacks. Put them on for about 20 minutes before anyone looks for a vein. If there is any vein there, it can be found after the hotpacks; it saves everybody a lot of difficulty.

Sleeping Position and Numbness

If you sleep on your side, your arm does not belong under your chest wall.

Your arm belongs either in front or in back of it, usually in front of your chest wall. If it is directly under your chest wall, then your rib cage is pressing on the nerves and the blood vessels going to your arm. Some of your numbness during sleeping may be related to this.

Edema of the Lower Extremities

For those of you who have edema of the feet, the amount of back pressure that has to be used to prevent this is considerable. You can learn to live with it if you do not want to wear something restraining, such as Jobst stockings. Jobst stockings, if they are going to fit on your feet, have to have zippers on them. They are made with zippers for the burn patients, so they can be made with zippers for your kind of problems as well. Jobst stockings are easier to apply to a paralytic foot than simply trying to pull up a really tight elastic stocking.

Lower extremity edema appears to be worse if there are any constraints on your abdomen and upper thighs. For the people who sit completely erect and are braced with the abdominal apron cutting into the anterior thighs (where the venous lymphatic return is coming back to the heart), either tilt your wheelchair back a bit or make sure that you have a broad elastic piece in the garment at that area. This way, you do not have something cutting directly into the tissue.

Skin Problems in Quadriplegics

Skin problems are very common in the quadriplegic person. Sometimes when a fungus infects one nail, it will quickly involve a number of nails. We have a fairly effective local preparation by the name of Lotrimin (clotrimazole) which can be applied rapidly when you see fungus in one nail, so it does not infect all the nails. This is useful both for hands and feet.

Difficulty with Mouth Positive Pressure or Glossopharyngeal (Frog) Breathing

At least three times I have seen people who could usually do mouth positive pressure or frog breathing suddenly find that the air was coming out of their noses. In all three instances, the patients had a straight neck, i.e., a soldier's neck. They had lost their normal lordosis.

In each instance, the difficulty was temporary. In one girl, it occurred during sleep when she had a post-nasal drip, and it lasted for about two weeks. In another boy, it was also for about that period of time. He didn't know mouth positive pressure, but his frog breathing was leaking out of his nose. When he had learned mouth positive pressure and had a good rest in the iron lung, the frog breathing became good again. In the third person, it lasted for about a half hour, then it disappeared. It had occurred in a completely flat position in bed.

Swallowing Problems in Post-Polios

Swallowing problems frequently occur in the individual who has lost the lordotic (anterior) curve in the neck. Speech therapists in rehabilitation programs today have been taught to work with patients who have swallowing problems. It would be worthwhile to visit one of them and have them point out what the swallowing mechanism is and how you can save yourself from choking.

One of the easiest things is the "think-swallowing" technique. In other words, before you try to swallow something, chew it thoroughly and think about what you are doing. You should not be laughing and talking at the same time that you are trying to eat. You should always eat in an upright position with your head tilted a little bit forward.

Dental Problems with Mouth Positive Pressure Breathing

With the use of mouth positive pressure, teeth can sometimes become a little loosened, especially in the lower jaw. This is very rare, fortunately. Sometimes teeth slant outward and require bracing. Your dentist can correct this problem for you.

Occasionally, I have seen an individual who actually used a bite block in his mouth at the same time that he used a mouth positive pressure mouthpiece. That is a little dental prosthesis to protect the teeth.

The Easy Way to Learn Glossopharyngeal (Frog) Breathing

All of you can learn frog breathing, unless you have a weakness of the oropharynx. The way I have taught people is extremely simple. Start by using the word "gup," from guppy fish. As you say "gup," you are putting your lips and tongue in exactly the position you need in order to frog. Usually about half of the audience can be frog breathing immediately by saying "gup." You are supposed to "gup" at the rate of about 100 times a minute, stopping every 12 to 15 seconds to exhale.

Glossopharyngeal (frog) breathing is very similar to clapping your mouth. I do insist, if you do not know anything about it, that you do make the sound, so you do not start doing something other than "gupping." One of my colleagues about five years ago decided that "gulp" was

better than "gup." And, of course, this is exactly what you are doing. It also works very well, and you do not have to open your mouth widely.

Some people start throwing their necks back; some swallow the air into their esophagus. None of these movements is necessary. Simply say the word "gulp" or "gup," whichever you choose. It should be a guttural sound way in the back of the throat. You can place your fingers against your throat if you are able. You will find that the floor of your mouth descends as you are saying it, and the ball of your tongue goes back against your hard palate. This is exactly what we need for frog breathing. If you want to strengthen the technique, you simply resist the lowering of the floor of the mouth with your fingers. The resistance will give a stronger musculature in your oropharynx to frog breathe.

I cannot emphasize the usefulness of this particular technique too much. I have seen people with no vital capacity who have frog-breathed for 25 years from a few minutes to several hours a day, and they maintained a beautifully compliant chest wall and lungs. The more compliant the chest wall and lungs, the easier it is to breathe.

So, if you do know frog breathing, you should be doing it about once every two to three hours during the day for five minutes, at a minimum. Many of you will use it as you speak or if you are engaged in any kind of exercise. If you use it, also use it deliberately as a deep breathing technique to maintain compliance of the lungs.

Do Not Smoke!

The hazards of smoking are, of course, enormous for the individual who already has some respiratory compromise. The main problem is that you have more mucus in your lungs when you smoke.

Many of you have read the news-

papers lately. "No smoking" also goes for your partner. If you don't smoke and you have a husband or wife who smokes, you are affected by that smoke. This is something you might discuss at home. All kinds of acute bronchitis and pneumonia last longer in the individual who smokes than in the individual who does not, and the infection is always more severe.

Influenza and Pneumococcal Vaccination

I would suggest that you all get your flu vaccine in the fall. The other vaccine that many internists recommend -- and I would recommend it for any person with compromised respiration who is living in the community -- is the pneumococcal vaccine. The side effects of the vaccine are practically nil, and it will prevent you from getting pneumococcal pneumonia, a very common type. Since the disease can be fatal and since there is a vaccine available, there is no reason you should not use it.

Complications of Tracheostomy Cuffs

If you need an inflated tracheostomy cuff, the main thing to remember is to keep it deflated as much as possible. This way you will not have the problems created by the pressure of the cuff on your tracheal wall. If you can do without a cuff, so much the better. Most patients, unless they have a severe degree of oropharyngeal weakness, do not need a cuff when they have a tracheostomy, unless they are unconscious.

Gastric Dilatation in Quadriplegics

Gastric dilatation was one problem I saw quite commonly in the early days of polio in the quadriplegic patient. I have not seen as much of it recently. It usually comes from dietary indiscretion, including alcohol, or possibly from an acute infectious process or renal colic. The main thing is to recognize it as an abnormal

pressure -- a pain under your diaphragm usually on the left side -- and then notice that your upper abdomen is distended.

The treatment is to get a nasogastric tube down as rapidly as possible. You may have to leave it down for a period of 24 hours with intermittent suctioning. During that time, obviously, your fluid needs have to be supplemented by IV fluids.

Constipation in Quadriplegics

We have a number of concerns about constipation. I will tell you just one little story. We had one quadriplegic who was using 90 cc of milk of magnesia a day, plus cascara and Colace. I had told him that, if he would just start eating enough bran during the day, this probably would not be a problem for him. He finally took my word for it, and now he says that he's down to no laxatives other than 5 cc of milk of magnesia a day and that he doesn't dare give it up because he's afraid. After years of constipation, it is beautiful to see he had gotten a good result. It is the treatment of choice, recommended by most gastroenterologists.

The only problem with bran is that if you do not get a fairly rapid bowel movement then you have the problem of fer-

mentation in your gut, and you may have more gas. In that case, it might be good to use other stool softeners in addition to the bran.

Renal Stones and Their Prevention

Renal stones were fairly common in the earlier days of polio. The staghorn calculus -- the conglomerative stones of the kidney pelvis -- occurred in the individual who was completely flat on his back 24 hours a day, seven days a week. That is why it was so common when everybody was confined to an iron lung and not easily turned from side to side.

If you have to go to bed, at least spend some time in a partially elevated position. Apparently the effect of gravity on urinary drainage is a factor in helping prevent the sedimentation or precipitation of salts in the renal pelvis. So turn from side to side, and get over on your stomach as well, if you can.

Atrophic arthritis of the hips can occur in quadriplegics where the joint space becomes narrow. There is a little sclerosis on the edges of the joint surfaces, and the condition can be quite painful. Lowering your trunk by simply reclining in your wheelchair may help this to some degree. There are a lot of other treatments for arthritis as well.

SOLVE THE ISSUE

Harriet Bell

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Contracted polio, is quadriplegic, and is ventilator-dependent

As a result of an article in the Rehabilitation Gazette, which estimated that 250,000 people who had polio are still living, a post-polio questionnaire was designed by Harriet Bell and Florence Weiner of New York City.

Although they have worked with no financial support, data collection and analysis continue with the volunteer assistance of friends. Data are now being entered into the computer, but the number of variables may preclude clear conclusions.

However, certain trends are evident. Polio survivors are around 38 or 55 years of age, have a high education level, including many with advanced degrees, and feel isolated, deserted, or dropped. If they were weaned from respirators, they often show signs of shortness of breath, interrupted sleep patterns, and depression. Many people have gastrointestinal problems. The same medications are prescribed across the country. Polio survivors are looking for capable doctors. Those being trained at the present time are unfamiliar with acute or post-polio problems.

A central information resource center is needed, one that will serve polio survivors across the country.

* * * * *

Our Post-Polio Questionnaire

In the Rehabilitation Gazette, it was

estimated that there are 250,000 people who may have had polio. There are 6 to 8 million children in this country who have not been inoculated. In the 1980 issue of the Gazette, Gini Laurie published a post-polio questionnaire by Florence Weiner and me, which was distributed to approximately 6,000 people across the country. There was very little response at that time.

Since then, there has been a tremendous response to this questionnaire. It has been disseminated by mailings throughout the country and by word of mouth. I am sure all of you received a copy yesterday.

We have done everything on a shoestring -- or really, half a shoestring -- because we have had absolutely no financial support. Volunteers help with the statistics. Everything has been done through friends who are interested in the people who have had polio.

The Early Results of Our Survey

It is a little early to tell you what we have learned. The data are just going into the computer. I do not think we will ever have clear data, because there are too many variables. Each questionnaire is a story by itself. Some people write ten pages, some write two pages, and some people fill in only three questions. Each one is so different, we may never know exact percentages.

Age Distribution

There are some very interesting things we do know. For instance, the majority of the polio-survivors are around 38 or 55 years old. Most of us were caught in the last polio epidemics just before the Salk vaccine. People were either young adults or very young children.

As we have heard, people who had polio tend to have a very high education level. Many, many people have advanced degrees; several are PhDs and several are MDs.

Clear Emerging Patterns

Certain patterns are beginning to show, even without a computer analysis. For instance, when someone checks "yes" in answer to, "Were you weaned from the respirator?" most likely "shortness of breath," "interrupted sleep patterns," and

"depression" are also checked.

We turn the page and it states, "I need a doctor but cannot find one." Many people realize that physicians now being trained, who have never been exposed to acute or post-polio, do not know how to treat polio survivors. Many have gastrointestinal problems. Many take the same medications. Many feel isolated, deserted, or dropped.

Future of Our Survey

For our project, we did not apply for grants or other funding, believing that we must establish credibility first. After we have received at least 600 completed questionnaires, we will begin applying.

There appears to be a definite need for a foundation or national resource center where information could be gathered and disseminated to polio survivors throughout the country.

SOLVE THE ISSUE

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From personal experiences with polio patients, three practical suggestions are derived: (1) know yourself, know your own level of function, and talk to your therapist about the way you handle activities; (2) be assertive with doctors and therapists; and (3) accept changes in your level of functioning and try to understand the secondary mourning and depression that are apt to ensue from such changes.

* * * * *

I am here primarily because I have been married to two different men who had polio. My first husband died in 1972. He was a respiratory polio, and my present husband is a polio paraplegic. I am also an occupational therapist.

Two Recent Experiences

I want to give you two examples of incidents that happened recently, one in my professional life and one in my home life. Then, based on my experiences, I will make three suggestions.

Johns Hopkins Hospital, where I work, is a large acute treatment hospital. A few months ago I was asked to come in on the case of a man in his late sixties who was on a surgical floor. He had some sort of uncomplicated abdominal surgery, very straightforward. This gentleman had polio several years prior; by the time I got to the situation, it was a crisis.

He had been in the hospital for three weeks. Prior to this time, he had been functioning independently. He stood to transfer, and he used a wheelchair. His

wife did not have to help him with any personal care. Now he could not come to a sitting position. He definitely could not stand to transfer. His wife said she couldn't take him home, that she didn't know how to do these things. The young physical therapist said to me, "Jay, you know something about polio. Come and look at him." The therapist had looked at his legs, and she did not believe that three weeks prior he could have stood up.

After looking at him and talking to him, I decided that the surgery did not paralyze him any more. He had been standing. He just didn't realize how much weakness could appear after three weeks of being in bed. He had not been in the hospital since he had polio. In further talking with him, I determined that the mattress was too soft, and he could not get the leverage he needed. We were able to get this man transferred to a rehabilitation unit. Rehabilitation is something abdominal surgeons don't think ahead about; they just do not think their patients are going to need it. With a few more weeks of muscle strengthening, he was able to go home, and he could stand to transfer.

The second example is from my personal experience. Dr. Bailey says that she does not know many polios with rheumatoid arthritis. Well, my husband has it in both wrists. It was not diagnosed at first. He was sent by his internist to an orthopedist who gave all kinds of other diagnoses. It was not until more assertiveness got him the medical care he needed; namely, a rheumatologist who diagnosed correctly. By putting my husband on the correct regimen of drugs, his pain dimin-

ished to the extent that he could function again. His level of functioning did change. For 40 years, since the onset of his polio, he had been walking part of the time with braces and crutches. Arthritis changed his whole method of functioning. He had to use sliding boards to transfer. His ability to go up and down stairs was eliminated. We had to make some home adaptations, and he could no longer walk at all. All this caused psychological problems in that he was adjusting to a whole new life style, and that wasn't easy. My husband will be 60 next year.

Three Practical Suggestions for Individuals with Polio

From these examples, I want to point out three things. Since most of our discussions have focused on what the group as a whole can do, I thought I would direct my three recommended actions to what individual people with polio can do.

The first suggestion is Socrates' old saying, "Know yourself." You have been doing things for many, many years in a style that is often not "normal." Therapists are trained to work with people who were normal prior to whatever happened. When you go into the hospital for a general surgical condition or a new disability that may or may not be related to polio, that changes your level of functioning, and health-care personnel may not know what to do with you.

You really need to be able to talk to your therapist and explain exactly how you did whatever the activity was -- the transferring, the standing up, or whatever -- because that will speed up his ability to work with you and get you back to the best level of functioning possible. You think you know exactly how you do things, but if you have been doing them for 40 years, maybe you cannot describe them accurately. If you suddenly were to lose the ability to do something, it would be very nice to have a clear picture so you could tell the therapist, "This is where I put my hand; this is how I did it." It will help in dealing with the medical profes-

sion if you think through how you do things and have a really clear picture of the activity.

The second point is that I think you need to be assertive with both doctors and therapists. It would be helpful if you could go to centers where everybody was trained to work with people who have polio, but I do not see that happening immediately. So you are going to have to deal with local doctors and therapists who may not know a great deal about polio. You need to do some negotiating about your condition. You can talk to therapists, argue with them, and get different opinions about the therapy needed. You do not need all of the modalities they have to offer. You will want some help on an immediate problem. You can tell the therapist that you will explain exactly what the problem is and what you did before. Give him as much help as you can, but make him responsive to you. You do not necessarily have to put up with a lot of pain or nonfunctioning. Make your doctors investigate the different problems. I think that any consumer of medical care has the right to be assertive and to try to make the medical profession responsive to him.

The third area is a suggestion concerning the psychological problems mentioned this morning. If something happens that dramatically changes your level of functioning, you almost need to go through a mourning period, just as you did originally. You are facing a brand new situation. One of the difficulties with this is that people around you do not see it as traumatically as you do. For instance, a little more weakness or sore wrists that prevent you from being able any longer to stand up may not seem like much to your family. But to you, it makes a lot of difference. I think you need to realize that some depression is perfectly in order and normal. You are going through the same kind of period you went through way back there years ago, and just understanding that this may happen to you may help you come through it. You all came through it the first time, and I know you can come through it again.

SOLVE THE ISSUE

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The best way to approach the issues at hand is, first, to analyze and define carefully one's questions. From the right questions will come the right answers. Three questions are posed:

1. Is there a late loss of muscle function where the nerve supply was involved earlier with polio?
2. Is the loss of function primarily nerve cell and muscle cell loss?
3. What is the cause of the loss of function?

The answer to the first question seems to be yes, but interpretations are conflicting; to the second and third questions, sufficient evidence is lacking for a definitive answer. For health evaluations and general health maintenance, it is important that post-polio survivors visit a respiratory rehabilitation center regularly.

* * * * *

We Must Ask the Right Questions!

The analysis and the solutions we are seeking depend on defining the issue. By that, I mean asking the right questions. If you do not have the question, it does not do much good to have a lot of data.

The First Question - Is There a Late Loss of Muscle Function?

The first question we should ask is, "Does delayed progressive dysfunction

occur in muscle groups whose nerve supply was involved with polio some decades before?"

I think most of us are saying yes to that question: there does seem to be some delayed loss of function. This was described over 100 years ago by a renowned neurologist named Charcot. Subsequently, there have been a number of descriptions of delayed increase in paralysis. But in many of these accounts, the authors may be dealing with two different diseases. There is really nothing to protect the patient who has had polio from progressive motor neuron disease, such as ALS.

As was mentioned earlier, there may be some genetic predisposition to these kinds of neurological problems, but that does not mean the development of two neurological diseases is very common. I think that many of us who work with polio patients have seen ALS appear some years after recovery from acute polio, with the first symptoms developing in the extremity that was involved in polio. We do not think this has anything to do with polio; there are certainly a lot of people with ALS who never had polio.

In an article by Campbell, et al. (Neurology 19:1101, 1969), describing five cases of delayed onset paralysis in people with polio, the authors emphasized that they differentiated this from progressive motor neuron disease and ALS because it was self-limited. These cases were anecdotal reports, and the relation to poliomyelitis may be coincidental.

We have heard today a number of reasons why people with muscular disease develop increased disability with aging. Is this "premature" aging? Certainly, premature chronologically, but not always premature in relationship to the loss of function that already existed. I think we can say that the first question was answered yes, but with conflicting interpretations.

The Second Question - Is the Loss of Function Primarily Nerve Cell or Muscle Cell Loss?

Second, we need to ask, "Does this loss of function occur in certain muscles more than other muscles previously involved?" I do not think we have sufficient evidence to answer this. We have heard about the EMG studies showing that changes can occur in certain muscle groups. How does this apply to other areas? Is there some specific use of an extremity that is associated with the loss of function?

Once we know the answers to these questions, we need to determine whether this dysfunction is primarily muscular, or whether it is due to nerve cell degeneration. Loss of motor nerve cells occurs normally. Perhaps, if you have fewer nerve cells to a particular muscle, it is going to give you trouble sooner.

Is the functional loss primarily neural? Is it simply due to the normal loss of motor nerve cells? These are burning questions for many post-polio survivors. Some diseases are described as due to "slow viruses." Does the polio virus also produce slow virus disease? The answer to this is that nobody knows for sure.

The Third Question - What is the Cause of the Loss of Function?

Third, we need to ask, "What is the cause of loss of function?" About this, we do not know anything for sure. What we do know about the polio virus is that it

does not behave in cell culture the way the so-called slow viruses do. The polio virus tends to destroy the cell within a period of a week or so, and it is susceptible to the body's defenses, such as the antibodies. The slow viruses multiply within a different area of the nerve cell and are not susceptible to the body's defenses. These are differences that we know about.

There have been some people who define "slow disease" as anything over four weeks, meaning that the virus survives this long. This has been described with polio in congenital immune-deficient infants who have been given live polio virus with Sabin vaccine. They were unable to handle it and developed a progressively fatal disease. That is the only report I have noted where a progressive process in polio that does not run the usual course has been demonstrated. Some people speculate that muscles with vascular change and scarring may undergo muscle degeneration with time unrelated to nerve cell loss. This may be a contributing factor in functional loss.

What Do We Really Know?

Of the three questions I have posed, only the first question seems to be answered, and this with conflicting interpretations. We need to define our questions and carefully analyze them before we can better approach the solution.

The Need for Regular Health Evaluations in Post-Polio Survivors

Other things I wish to mention are a little more directly involved with what you people will be doing. We have already discussed the need to have regular evaluations. I know many polio patients, who, once they left the hospital, haven't gone back unless they just had to. They are tired of being around health professionals. They have learned to live with their disability, and they do not want to get "checked in" to a hospital.

I think there is a time, though, when you have to give up that attitude and find a good, knowledgeable physician and/or physical therapist. You need muscle testing. You need a baseline from which to decide whether or not something is getting weaker. Muscle strength has to be evaluated. Another need is for health maintenance, other than just following up functional muscle strength. As you know, many of you have increased susceptibility to respiratory infections. If you do not get your maintenance, such as vaccines, you are at increased risk compared to the general population.

You may have heard that the annual physical is not very productive. For the general population, it is probably more productive for the doctors than for the

patient. However, I think a group of individuals with chronic illness -- a group which has had disabling disease -- is different. In the case of post-polio survivors, I believe health maintenance evaluations are essential.

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PANEL DISCUSSION - INTRODUCTORY REMARKS

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The level of meshing and working together among various groups from every corner of the nation, and with people from other nations, is something for which we are all very grateful and which I hope we can continue in future meetings. We have raised the vital issues and started working together. I think this is an enormous accomplishment.

You have an impressive number of questions for discussion. Most of them fall into six categories: (1) general medical problems; (2) exercise and pain; (3) specific cardiovascular problems; (4) specific respiratory problems; (5) the definition of problems related to polio; and (6) financial issues and organizational assistance.

* * * * *

General Medical Problems

Osteoporosis, Calcium and Renal Stones

Dr. Goldberg: Is osteoporosis something ongoing and lifelong, or is it most severe the first couple of years after contracting polio? If it is lifelong, should there be a dietary restriction of calcium?

Dr. Alba: Osteoporosis is a thinning of the bones that can occur from immobility at the onset of polio. It occurs because the muscle tone is completely absent. The individual is flaccid. So the pull on the bone is missing.

The process is more severe during the first one to two years following polio. Then, there is a stabilization and an equilibrium established between the amount of calcium that is taken in, the amount in the bone, and the amount that is excreted.

As to whether or not you need a dietary restriction of calcium: theoretically, if you were post-menopausal, which many of the women here are, you should need your regular intake of calcium every day.

When I first got into this, patients were telling me that they could take chocolate milk instead of regular milk, because it had phytic acid in it. The phytic acid would become calcium phosphate, which would remain in the gut, be excreted, and not be absorbed. Therefore, they could have milk products that way.

I wrote to the National Institute of Metabolic Disease about this, and they told me that what you put into your mouth has nothing to do with what occurs in your urine. From the radioactive studies that have been done, the indication is that you do not have to worry about calcium intake in terms of whether or not it will result in renal stones. Certainly, if you have an overweight tendency, you should have about a pint of skim milk daily.

Extra Weight Gain

Dr. Goldberg: Does extra weight gain compound the problem of polio survivors?

Dr. Maynard: I would say yes.

Dr. Fischer: Weight gain does compound the problem. It compounds all kinds of problems. If you have a weak extremity and you try to support added weight, you are going to have more trauma to the knee and perhaps also to the hip.

Extra weight also seriously influences your capacity to breathe. There are people with perfectly normal lungs and perfectly normal muscles and nerves who gain so much weight that they have to be put on respirators because they under-breathe, particularly at night. These people are not always massively obese, although most of them are. By "massively," I mean 400 or more pounds. They have both inadequate breathing and some irregularities in their nighttime breathing.

Dr. Alba: You may have to take as little as 800 calories a day not to gain weight if you are confined to a wheelchair, because the older you become, the fewer your metabolic demands are. Oxygen consumption goes way down. If you are a quadriparetic or quadriplegic, your oxygen consumption is only half normal. When you add normal aging to that, oxygen consumption and metabolic demand is even less.

If you have to take in fewer calories not to gain weight, you must supplement your diet with mineral and vitamin supplements. This is one time the one-a-day vitamin and mineral are important.

Creatine Phosphokinase (CPK)

Dr. Goldberg: What is the relationship between creatine phosphokinase (CPK), blood level, and accelerated nerve cell loss?

Dr. Maynard: The problem is how to explain the CPK. It is an enzyme whose content is particularly high in muscle. Measurement of this enzyme is probably the best reflection of muscle fiber destruction. In my opinion, a CPK count of two times normal would be difficult to interpret. I am a little reluctant to say that it would be of no concern at all to me.

There are several problems. You can have raised CPK levels from other causes, illnesses other than just muscle disease. And there are other tests you have to look at. Two times normal is in the range where it is really difficult to interpret when somebody has had polio. They may have a slow release of CPK that remains above normal chronically. If it were truly going up with time, I guess it would be of some concern.

Dr. Alba: There is a variability in the CPK from one test to the next. If you have been lying around in bed for two days, it is going to be elevated. So if you had 30 one time and 50 the next, that would not mean the level is rising, because you may have 30 again the next time.

Dr. Maynard: I would like to add that you have to standardize what your activity was in the 12 hours before the CPK test was done. CPK goes up in normal people after vigorous exercise. Then we get into the issue of what constitutes vigorous exercise for a person who has had polio. Pregnancy, other conditions -- there is no simple answer.

Dr. Doneff (from audience): One caveat occurs to me when the question comes up about CPK. If any of you were under continuous care from a particular doctor, I would say that lab results are probably quite meaningful. But if you are going in as a brand new patient or you haven't been seen for 12 or 15 years, somebody has to be aware that, by the very nature of your illness, your laboratory values are often different from accepted norms.

If you have something that is in an abnormal range and somebody makes a vigorous attempt to correct it, he may well do you more harm than good. If you fall into the hands of someone who has an established trigger mechanism on how to handle abnormal lab values, he may jump in too vigorously when it would be better to do nothing until your natural base line is known.

Alcohol

Dr. Goldberg: What is the long-range effect of excessive alcohol consumption on the post-polio survivor?

Dr. Fischer: There are bad long-term effects on anybody if alcohol is consumed excessively. The problem of what is excessive varies from person to person. Some people refer to an alcoholic as someone who drinks more than they do!

We have to consider what effect alcohol has on the individual. Obviously, daily consumption of four or five drinks in some people might not show up much. In a person who has had polio, however, you are dealing with somebody whose nervous system is more susceptible to the effects of alcohol.

For instance, if you have a weak muscle, if you are naturally apt to fall, obviously by having a drink you are reducing your margin of safety and are at much higher risk of falling. Also, alcohol interferes with nutrition. People who drink a lot do have a greater tendency to aspirate. People who have had bulbar polio have no particular symptoms until they have a drink. Then they find that they cannot swallow very well; food and liquid go down the wrong way occasionally.

My answer to the question is that the long-term effects of alcohol are the same as for everybody else, but more so. The greater risk depends upon the kind of polio involvement you have.

Dr. Alba: With alcohol, remember, if you are using mouth positive pressure with or without a lipguard, or if you have had any indication of sleep apnea, central or obstructive, you should not have alcohol at bedtime. Have it during the day, but not just before bedtime.

Judy Heumann: What about pot (marijuana)?

Dr. Alba: Pot is in the same category. So, too, are any of the tranquilizers, sedatives, relaxants, anything which is a neural depressant.

Sex Drive

Dr. Goldberg: In post-polio survivors, should there be a decrease in sex drive, say, at age 50?

Dr. Fischer: The subject of sex is not often brought up in groups, though slightly more now than it used to be.

There are several pathologies associated with it. I do not think there is any difference between a patient who has had poliomyelitis and anyone else as far as sexual needs are concerned.

The age factor is not what it once was thought to be. For many years, sexual activity was thought to be something you didn't expect from a person who was mature and over 50. However, that is obviously a cultural fantasy. Certainly, sex goes on quite effectively in many individuals throughout a long life, including octogenarians.

I think whether the sex drive decreases depends on what you mean by "sex drive." For instance, we wonder how teenagers ever accomplish anything, because for 60% of the time they are thinking about sex. If that is sex drive, then it tends to decrease after 50. But as far as performance is concerned, there is very little change in normal individuals. If there is change, it is usually a result of chronic illness. Many times it is a psy-

chological problem reflecting a concern with failure and things of this nature.

Sexual counseling is available from a lot of places now. Sometimes just talking about it with one's partner is the best solution to the problem. If you do that, it solves itself.

Barbiturates, Sedatives, and Tranquilizers

Dr. Goldberg: As the aging polio survivor becomes more anxious about aging and the symptoms he experiences, do barbiturates, sedatives, and tranquilizers pose a risk when there is chronic respiratory insufficiency?

Dr. Alba: There is a very large risk in taking tranquilizers and sedatives if you have any components of any respiratory insufficiency.

I looked at the paper of Dr. Ann Bailey who commented that only two respondents spoke about respiration. But five respondents spoke about the throat, which is the problem of aspiration, as Dr. Fischer pointed out. If you have generalized weakness, you may very well have weakness which affects your muscles of respiration. Those 22 people who had trunk weaknesses also may have had weakness of the respiratory muscles. So that entire group which represents at least 25% of Dr. Bailey's study would have to worry about sedatives and tranquilizers.

Bladder Problems

Dr. Goldberg: This last general medical question is a good example of the confusion I often hear. A person writes, "Having had polio 31 years ago and recently having had a bladder problem, namely, urinary frequency, the urologist believes it to have been caused by polio." The writer does not believe this to be the case. Is the condition possibly related?

Dr. Maynard: No, it would seem

unlikely that anything having to do with the polio would affect urinary frequency, unless it was a urinary tract infection. I think the danger would be if there were some progressive weakness. The polio complication would be in emptying the bladder, as it is controlled by the bladder nerves. With weakness, there could be incomplete emptying, which can predispose to infection and then frequent urination. I would presume that this would be diagnosed by simple urinalysis.

Exercise and Pain

Exercise Regimes and Swimming

Dr. Goldberg: What exercise regime is appropriate? What about the use of swimming pools, passive range of motion, etc.?

Mary Jay Bullock: Passive range of motion, for example, means that either you move the arm that does not move with your mobile arm or someone else moves it for you. It won't make anything stronger, but it can be used to prevent contractures. The only way to ever make a muscle stronger is by actively using it.

You should set yourself a program of passive range of motion that makes sense. If you cannot move your joint through a complete range of motion, you need someone else to do it for you, say, three times a week. You will probably be able to maintain your range of motion for all practical purposes, but no amount of passive range of motion is going to make you stronger. It is simply keeping your joints stretched out.

Dr. Bailey's survey noted that swimming is one of the things people did do. Swimming is one of the very good movement exercise programs for a person with paralyzed muscles. Many people who cannot jog can swim very well. You can swim with only your arms, and as long as you are not too ambitious about it, it would probably be a very good exercise.

Dr. Maynard: I support that. Swimming is one of the best forms of exercise. You still have to watch out for fatigue, and you certainly could overexercise yourself in water, but you are not likely to because of the nonweight-bearing effects on your joints.

If you do have stiffness in your joints, swimming helps. The pool is also an excellent place to do range of motion exercises and stretching out. By swimming, you are maintaining muscle flexibility and preventing true contracture in the joints. People who have had polio are not as predisposed to joint contractures as are many others who have muscular conditions. However, contractures are something you need to watch out for.

Dr. Bailey: I would like to add my voice to that. I think swimming is one of the best exercises that people who have had polio can do. I would like to caution that the water should be warm because we have found that cold is detrimental. One thing that probably has not been mentioned is that you should definitely avoid chilling.

Breathing Exercises

Dr. Goldberg: Are there any breathing exercises that might be helpful?

Dr. Fischer: Breathing exercise is a term that takes in a lot of things. I think it is important for people to maintain chest mobility. What we have referred to as "chest stretching" is a process you might call a chest or breathing exercise. Many people who need this use frog breathing, but they tend to get away from this. Sometimes they use routine mouth positive pressure to stretch the chest and keep it limber. Otherwise, there is a tendency to lose a lot of breathing capacity.

If you have a problem raising secretions, you may want to consider an exercise. If your abdominal muscles are gone

and you have lots of secretions, it is important to try and get those up either with vibration, with assisted cough, or things of that nature.

There is evidence that you can strengthen the diaphragm by exercises such as working against limited weights and so on. This is true, at least in traumatic quadriplegics. It depends a little on what you have left. If you use excessive weights with few neurons present, you may end up worse off than you were. Such exercise should be done with some advice from the physical therapist and from people who know your type of diaphragmatic function and reserve.

Pain Management

Dr. Goldberg: For the polio survivor now experiencing pain, what have you found to be most helpful in managing this pain? Heat, cold, drugs, biofeedback?

Dr. Bailey: I will make an effort to provide an answer, but we really do not have a very good one. The usual pain from joint stress or muscle strain responds to the same things we use for other patients. But the particular pain I mentioned previously, the one post-polios have been concerned about at Warm Springs, is resistant to easy management. It does not respond to the usual analgesics and can persist despite almost anything. If any of you have found some answers, I would like to know what they are.

Dr. Maynard: I would stress that heat is much better than cold. This is empirical. It definitely is worth a try and cannot hurt when properly applied. The hot tub is popular, especially in California. Drugs can be helpful. I prefer anti-inflammatories such as aspirin. Avoid any type of strict analgesic, and certainly avoid narcotics.

Dr. Alba: There is just one other point. It was reported a few years ago that, if you are an insomniac and miss many hours of sleep during the night, you

can develop increased pain throughout your body. Maybe your symptoms are exacerbated if you are not sleeping well. So all the ideas we have to give you about improved sleep would lessen your pain.

Specific Cardiovascular Problems

Heart Rate

Dr. Goldberg: How do we increase our heart rate and not exhaust ourselves?

Dr. Alba: Heart rate is directly proportional to the amount of exercise you are doing. The exercise is rated in terms of what are known as "mets." The "basic met" is your energy expenditure at rest. The amount of oxygen that you use above and beyond that is simply determined by dividing the basic into the amount you are using. Your heart rate is proportional to the number of mets that you are using.

Wheeling definitely increases your heart rate, and hearts are strengthened by wheeling. I don't know quite what is meant by "enlarged." We would hope that the muscle fibers may be enlarged, not the heart chambers. There is some hypertrophy (muscle wall enlargement) of the heart by any exercise you do. In severe quadriplegia, anything you do might exhaust the heart. There are some hearts that will remain totally deconditioned as far as physical exercise is concerned.

The only other cause for an increase in your heart rate is emotional stress. I haven't found that those hearts are necessarily in any worse shape than one in which we have increased the average heart rate. The point of increasing the heart rate with exercise is that, when you are at rest, your heart will beat more slowly as a result of having beaten more rapidly when exercising. If the heart beats more slowly at rest, it is going to last longer. How convincingly that has been proven is another story.

Hypertension

Dr. Bailey: How about hypertension? Is this a post-polio problem? Does this seem to occur most often in someone with atherosclerosis, or is it due to poor circulation? Is it normal or perhaps related to shortening of blood vessels or capillaries? Should we take medication for hypertension, or let the readings remain high?

Dr. Maynard: There is nothing that I have ever read that suggests that diseases of the muscle would predispose in any way toward hypertension. Certainly if a person becomes hypertensive, it should be treated. I do not see any reason why a post-polio person would be any different. I also know of nothing that would suggest that there is something about having had polio that would predispose him to it.

Dr. Alba: The only thing I would like to add is that, for the simple treatment of hypertension, you start early in life on a low sodium diet, especially if you have family members with hypertension.

When you treat hypertension, you cannot be overzealous with drugs, because if you are a quadriplegic in a wheelchair you have to worry about postural hypotension, especially in hot weather when you have capillary dilatation of the skin. In treatment, there has to be a happy medium. The one feature you can remember is to keep the lower level of blood pressure, called the diastolic, below 100, if at all possible. The incidence of stroke in the older population has been very definitely correlated with diastolic pressures above 100.

Exercise and Cardiac Conditioning

Dr. Maynard: I would like to ask a question of Dr. Alba and Dr. Fischer relating to the last question. What do you think is the benefit from exercise for the purpose of increasing the heart rate and cardiac conditioning in a person who has had polio?

Dr. Fischer: It seems to me that you really cannot do that without the work of the skeletal muscle. As we mentioned before, there are some potential risks to excessive use of the skeletal muscle. You have to use skeletal muscle relatively vigorously in order to get the cardiac conditioning effect. I am not aware of any evidence to suggest that post-polio people have any greater incidence of heart problems. Yet, I suspect that as a group their activity level is much lower than that of the general population.

Dr. Alba: I would avoid the heavier exercise that would be necessary for cardiac conditioning. If you exercise strenuously, you will improve the collateral coronary circulation. I don't think it is worth the risk to the rest of your body.

Dr. Fischer: I would say I don't really know.

Dr. Doneff (from audience): I am by no stretch of the imagination a cardiologist, but I think that in no case should hypertensive readings be ignored. If your systolic pressure is over 140 and your diastolic over 90, your pressure demands treatment. You cannot do it yourself, because nothing you do other than maintaining a low sodium diet is going to influence it, as far as I know. Possibly biofeedback might have some effect.

I know of nothing unique to us polios that predisposes to hypertension. In 1958, I was told by an internist that it was well known in the internal medicine community that hypertension was a virtually inevitable consequence of polio and that this was true of all post-polios.

Hypertension is basically one of two types. By far the most common is what is called "essential hypertension" or "idiopathic hypertension." Usually you have to undergo a work-up to exclude the other type, which is renal hypertension. The work-up is mandatory because, if it is renal, it can usually be corrected surgically. If it is not renal, it is the type that everybody has, and the cause is unknown.

There is one other brief point that I want to make. The concept of blood vessel changes in polio is rather simplistic, and I think it betrays an ignorance of the vascular system. That is a real danger among us polios, because we are hearing things that most of us do not have the capacity to interpret. I would say talk to your family doctor or internist if you have a high blood pressure reading. Have it treated.

Dr. Spencer (from audience): I would like to add one caveat to this business about the recognition and treatment of hypertension in the polio survivor. I have been "called out" four or five times by an artifact. The difficulty is that you often have very small arteries and quite small limbs, and the normal method of measuring the blood pressure with a sphygmomanometer can very easily lead to artifact. As a result, one can be led to think that hypertension is present when, actually, if you measure it directly with a needle in the vessel, it is not present at all. I have improved a number of patients by stopping their hypertension treatment where it had been based on artifactual measurements in an abnormal limb.

Specific Respiratory Problems

Use of Antibiotics

Dr. Goldberg: Should antibiotic therapy be initiated at the first sign of any respiratory illness in a polio respiratory problem, or should it wait for definite evidence of bacterial infection?

Dr. Fischer: I suppose we may have some different opinions on this. The idea that you do not treat an infection until you have isolated the organism and tested its susceptibility is a universal "infectious disease expert" approach. This is often necessary when dealing with certain types of infections. If you have a serious pneumonia, you do not want to go in blindly or just take any medicine you can find. For severely ill patients with life-threatening

infections, you need to isolate the organism to know what you are treating and then use the "big guns."

When we are dealing with people with respiratory disease -- whether it is poliomyelitis, with inability to clear secretions or expand lungs well, which makes them more susceptible, or chronic bronchitis and emphysema, with impaired clearance of secretions and difficulties with recurring infections -- it has usually been accepted to initiate treatment before you reach the hospital stage. There have been studies indicating that this reduces the frequency of severe disability, although the studies have been questioned for accuracy by modern statisticians.

I generally give an antibiotic to those who have changes in the physical nature (color, thickness) of the secretions because they believe they have a respiratory infection, or know they are susceptible to deep chest infection. I try to stay away from the "big guns" that might be necessary in treating a more severe infection. I start with something like tetracycline or erythromycin.

Dr. Maynard: I would agree with you. I prefer early use of antibiotics with people with depressed respiratory capacity. The one caution I would put to the audience is the great danger of self-medication. Because you are obliged in early treatment to take prophylactic medication for at least a week, if you got over the infection and stopped the medication after a day or two, that is something your physician should know about. Treatment should be administered in conjunction with a physician who knows what is going on at the other end. If there is trouble later from antibiotic-resistant organisms, the physician needs to know what has already happened.

The other point is to promote coughing and drainage. They are probably every bit as important as the antibiotics.

Acceptable Drugs for Respiratory Care

Dr. Goldberg: From the point of view of medications -- for sleeping and tranquilization, for handling respiratory secretions, excessive mucus, etc. -- which drugs are safe?

Dr. Fischer: Are we talking about drugs to raise secretions?

Dr. Goldberg: One category is raising secretions. The other category is for sleep, relaxation, and tranquilization.

Dr. Fischer: I might just say my prejudice is against either one. There are an enormous number of expectorants on the market. These are supposedly agents which help, but there has been no really good documentation of the effectiveness of this type of medication. They are prescribed almost universally, more because people demand them than because doctors feel that they are useful. Iodides tend to be a problem because of the sensitivities that arise; they are commonly involved in some of the expectorants.

As far as tranquilizers are concerned, they are hazardous to your health if you are at all subject to reduced breathing. One can become a poor breather at night even without them. Alcohol is a tranquilizer, and so are Valium and Librium and Phenobarbital. Drugs like these have to be individualized and very carefully. For people who have had respiratory problems, they should be avoided at all costs.

Dr. Maynard: Grandmother's advice for good hydration -- lots of fluid when you have colds and some humidification in the air -- will do you more good than the medications for mucus. Sedatives and tranquilizers can be used with a physician's guidance for some temporary emotional problem -- the only excuse for even able-bodied people. If a person is having trouble sleeping, medication should only be thought of, realistically, as a short-term crutch. Once it becomes a chronic need, you are going to be in

trouble with drug dependence.

Dr. Alba: It is said that no sleeping pill is effective after two to three months. If you are taking one continuously, it becomes a problem of drug dependence.

The Definition of Problems Related to Polio

Post-Polio Referral

Dr. Goldberg: Where does the post-polio go for an analysis to determine what is post-polio related?

Dr. Maynard: People have asked that question many times during the last couple of days. Our bias is that you can be seen in an active rehabilitation center. What does that mean? It means a rehabilitation center that isn't just treating outpatients, but one that is involved with more general medical problems, including acute medical problems. The focus of an active rehabilitation center is a comprehensive team approach with physical medicine and rehabilitation, orthopedics, and pulmonary medicine. There you have the advantage of a complete evaluation -- orthopedic, neuromuscular, and cardiopulmonary.

Dr. Bailey: We had so many inquiries at Warm Springs about referral facilities that we put together a list of the rehabilitation facilities throughout the nation. We tried to refer every patient who inquired to the rehabilitation facility nearest him. We are greatly disappointed in the treatment they received. A very high percentage wrote us to say that they went as directed and found the staff to be totally unaware of polio problems. They were given excessive exercise programs, that sort of thing. One thing that needs to come out of this meeting is a registry of places that are familiar with polio problems because the usual rehabilitation facility does not seem to be.

Post-Polio Medical Education

Dr. Goldberg: Most doctors are not informed about the post-polio person. How can their patients get them to understand? Doctors are really doing post-polio persons an injustice by not being informed. Is there some method for getting the word out to doctors? We go to doctors for answers, but they don't have them. Then what? Dr. Alba, have you or your colleagues written any articles in any professional medical journals regarding the management of respiratory polios, especially their surgical or illness situations, which we consumers could get copies of to assist our physicians?

Dr. Alba: I have not written about polio specifically. In Respiratory Therapy, we have written four articles in the past five years on syringomyelia, ALS, multiple sclerosis, and, yet to be published, spinal cord injury. Actually, neuromuscular disease is managed almost identically in the acute or long-term situation. These articles would be useful for the respiratory polio, as well.

Post-Polio Surveys

Dr. Goldberg: These questions were asked about the surveys, their publication, and their future use. Where will one be able to eventually see these surveys, so the information can be spread among the medical, consumer, and service organization populations?

Ms. Bell: I would hope, if we get some funding, by the end of this year. Each person who has sent in a questionnaire will get some type of form letter informing him at just what point we are.

Dr. Bailey: Our questionnaire certainly is not as extensive as the New York questionnaire by Harriet Bell and Florence Weiner, but we do hope to complete our survey. We don't want to publish what we have already. But, if we are able to enlarge it to the point that the results are really reliable, then we will

try to make them available.

**Financial Issues and
Organizational Assistance**

Dr. Goldberg: We have had ideas about rejuvenating the March of Dimes, funding the Rehabilitation Gazette to distribute information, and hiring a full-time coordinator. So far, nothing has been

firmed up. Can we make something happen?

I think that we have, in fact, started something! We have worked together in five sessions to focus attention on the issues. We have looked at the past to see what can be considered to have worked successfully. It was a success because you are all here today so actively contributing to the study of the present. We must continue to work together for the future.

SUMMARY: Special Meeting held the evening of October 15, 1981

THE ISSUES THAT CONCERN THE POLIO SURVIVOR

Judy Heumann

Quite a number of people participated last night. The discussions showed the continuing diversification and organization in this country of persons who have had polio, which is quite encouraging.

There were discussions about the symptoms people were feeling as a result of their polio. Some people suggested we should not become hypochondriacs in our analysis of what was going on with our bodies. And there was a discussion about whether calling someone a hypochondriac was not also a way of denying the reality.

The symptoms that were described included numbness in hands when writing, problems sleeping and waking up, pain in joints, screaming at night to wake oneself up, no longer being able to lift oneself up out of a wheelchair, and mucus problems when breathing. Some people were afraid to discuss these problems because their doctors basically say that these symptoms are nothing.

Other concerns included heart pounding and not knowing what it meant, high blood pressure and what it means for the population that has had polio (what can be done about it?), hyperventilation and hypoventilation (what are they and how are they dealt with?), arthritis, and general weakness.

There were also questions about whether or not using the respirator could cause weakness and cause people to die earlier. Dr. Alba said that she would write guidelines for respiratory problems. They would include how to use a respirator and the issues for people having respiratory problems who may not have used a respirator since leaving the hospital.

People were concerned about not having listings of doctors who had information on polio, and they were concerned about the training of present-day doctors. If you were a severely disabled post-polio, what were the implications of not being able to get doctors to make home visits?

People want more help from the medical profession. For example, what happens if you are post-polio with a respiratory problem that you might not even be aware of, and you are taken to a hospital in an emergency situation? Let us say you cannot communicate effectively with your doctor. Would not a hotline be useful, so that emergency doctors could call someone to get information about what to do?

Other issues: Doctors are unreceptive, and people are made to feel as if their problems are all psychological. Discussions about wheelchairs and other technological devices could be liberating.

There were interesting perceptions about technical aids: for example, how a person sometimes saw the utilization of additional pieces of equipment as a sign of his deterioration and was, therefore, reluctant to use them.

We discussed vitamins and whether or not they should be taken. Some people said that if you believe they help you, use them; others said that vitamins have a positive effect, not just a placebo.

There was also a discussion about diet. Some people wanted more information about good nutrition and wanted to know whether there are foods that they should or should not eat.

We discussed the need for centers

where people who have had polio could go for treatment. The more polio survivors doctors see, the more experience they are going to acquire. We questioned who is going to pay for services. We stated that the March of Dimes needs to get more involved. One idea proposed was that we might use the military transport system if places people could go for treatment were identified. Perhaps the spinal cord injury centers could be used as regional centers for the treatment of persons who have had polio. There was a debate among some of the doctors as to whether or not the spinal cord injury centers really had the expertise to deal with post-polios who have respiratory problems.

Dr. Alba said that she would write to the March of Dimes and ask it to become more actively involved. We cannot let them forget us, since they are there because of us. A suggestion was also made that a letter be written to the National Institute for Handicapped Research. We need a committee to identify the questions that need to be answered, to make constructive suggestions, and to recommend legislation.

Marilyn Saviola

[Ms. Saviola is a Rehabilitation Counselor at the Goldwater Institute, New York. She contracted polio, is quadriplegic, and needs respiratory assistance. -- Ed.]

A lot of what we heard at the meeting last night -- and a lot of what came out yesterday and the day before -- was a common concern. Many of us have known people in the last few years who died unnecessarily, either because they couldn't get medical help when they needed it, or when they did receive it they were so overwhelmed by the idea of a more severe handicap that they chose not to accept the help. One of the things we agreed to be essential was that both consumers and providers try to gain a better understanding of the dynamics that

are causing this kind of reaction.

Gini Laurie mentioned something which I think really starts to look at the issues. In effect, what happens to people who are weaned from a respirator very early, then, 20 years later, have shortness of breath or diminished energy, or any of the other symptoms about which you have heard? What does it mean to them when they are told that they are going to have to use a respirator, have a tracheostomy or use an iron lung, intermittent positive pressure breathing (IPPB), whatever? Gini says it is as if after having overcome many obstacles, such as being weaned from a respirator, a trach, a rocking bed, etc., these persons, 20 years later, still haven't overcome all their problems, because they have new problems! It's no wonder people become discouraged.

Failing to live up to other people's expectations tends to make us believe we are "bad." Society tends to equate ability with physical ability and physical maneuverability. If someone becomes less physically able, he becomes less human. These are all part of the dynamics that we heard, along with questions about how to approach these problems and help people in these circumstances. It is not only a medical problem. It is a social problem.

We have many official and informal networks around the country. We have spinal cord injury centers, the Rehabilitation Gazette, and centers for independent living. Somehow or other, we have to develop a network system so that, when someone is in trouble or in doubt, he can plug into these systems on many different levels -- nationally, regionally, and locally. We have to come up with a method of addressing this; otherwise, at the next conference you have, there will be a significantly smaller number of us present.

One of the nicest things about last night was a real blending of professionals, providers, and consumers who shared concerns and feelings. It wasn't doctor to patient. It was people who are genuinely

concerned about problems that may affect people in this country.

Judy Heumann

Dr. Spencer was kind enough to stay up until about midnight. A lot of us who

stayed to talk to him realized that one of the things we have not been able to do is sit down and talk with a doctor, someone who knows something about polio and with whom we could talk about anything and everything we have been experiencing. Some of the very simple things that he talked about were really very effective.

SESSION VI

**THE FUTURE: CAN MODERN ORGANIZATIONAL
APPROACHES TODAY MEET THE CHALLENGE OF
COMPLEX PROBLEMS OF TOMORROW?**

OPENING REMARKS

Henry B. Betts, M.D.

Vice-President and Medical Director,
Rehabilitation Institute of Chicago, Chicago, Illinois

Professor and Chairman, Department of Rehabilitation Medicine,
Northwestern University Medical School, Chicago, Illinois

Surely a matter of the utmost concern to all of us here and to post-polio survivors throughout the world is what the future may hold. Here to present their views on this topic are our two speakers from London and Paris, as well as representatives from this country.

Finally, for the Keynote Address, we are honored to have with us Dr. C. Everett Koop, Surgeon General Designee of the United States. After Dr. Koop's address, we will close the symposium with a final General Discussion.

HEALTH-CARE PERSPECTIVE

Geoffrey T. Spencer, M.B., F.F.A.R.C.S.

Phipps Respiratory Unit, South Western Hospital,
Consultant, St. Thomas's Hospital, London, England

One definite future need is to maintain the valuable information service provided by the Rehabilitation Gazette, which has no equal in the United Kingdom.

There is a danger that the numerous speculations about post-polio aging may lead to unjustified comparisons and actions. An unrecognized threat exists of a renewed polio epidemic stemming from those parts of the world where polio is still endemic.

Accurate diagnoses of post-polio respiratory difficulties are extremely important, lest these symptoms be mistaken for other types of problems such as aging or heart trouble. The distinction between the respiratory disorders of the post-polio survivor and the person with intrinsic lung problems is also a critical one.

Future medical care for polio survivors requires that doctors see enough patients -- 300 to 400 on a regular basis -- to gain the experience needed to treat polio-related problems adequately. A total, comprehensive, and human approach is mandatory. We owe this to the polio survivor who is the reason for many of the advances in medical care which have saved millions of lives.

* * * * *

Predicting the future requires information that is only available to politicians and God, neither of which am I. The one thing that I can tell you, as a piece of godlike medical wisdom, is that life is a disease with a mortality rate of 100%,

and I think we should be able to talk about getting old without feeling either that it is scary or that we, the doctors, are shroud-rattling.

The Rehabilitation Gazette - A Unique Information Service

Research and statistics on aging are all very fine and necessary but do not provide an elixir for eternal life. From what I have seen in the last two days, what worries me most about aging in people with polio here is the way it will affect Joe and Gini Laurie, because I think they are providing a unique information service. I think your task is to find somebody who will take over.

I wish we had somebody like them in the UK, and I wish they would send more copies of their journal so that more people over there could enjoy it. We would benefit greatly. The British need somebody to help with the extraordinarily valuable work such as that done by the Gazette in this country.

Post-Polio Aging - Truth or Speculation?

Dr. Maynard this morning summarized very well the present state of knowledge of the electromyography of aging and the expanded territory of the post-polio motor nerves. His description of the mechanism of fatigue in the muscle weakened by polio was really quite excellent.

What worried me was that he moved

rather smoothly on to the field of speculation. His concept of what might happen to what he called the anterior horn cell previously damaged by polio is undoubtedly speculation. It is doubtful whether there is such a cell. It is more likely that once the virus got in, that particular cell ceased to exist. There is no regeneration in the central nervous system, and we are seeing adaptive changes in the remaining cells. I think that is the process occurring when patients regain strength after acute polio.

He also worried me by comparing the changes that follow polio with those in a progressive neurological disease such as ALS (motor neuron disease). I think this is dangerously speculative because it leads to the philosophy of throwing in the sponge. I am sure that many of the changes that you are experiencing can be corrected or alleviated by appropriate treatment or changes in your life style.

An Englishman's Perception of the Issues

Of course, it is easy for me to come over here for two or three days and talk to you like this because I am in a happy position of total irresponsibility and cannot be brought to account for what I say. Nevertheless, I am absolutely certain that the greatest danger in the future is that of another epidemic.

Polio is still endemic in large areas of the world and particularly in underdeveloped regions to which people travel in ever greater numbers. In developed countries we have forgotten about polio and think of it as a disease of the past. It isn't, and the levels of effective immunity in the population of developed countries are dangerously low. There is no country where immunization against polio is compulsory, either for residents or visitors. The World Health Organization spends millions trying to eliminate the last few cases of smallpox from the mountains of Ethiopia but does little about polio, except to state that there are still five million new cases in the world each year.

Travel companies refuse to mention polio immunization in their glossy brochures. They say it might put people off; comment is superfluous. Frightful scenes are made with compulsory international certificates for yellow fever, smallpox, cholera, and typhoid, against which available vaccines are more dangerous, uncomfortable, and less effective than Sabin is for polio. In all these illnesses, you either die or recover. I could go on and on like this but hope I've said enough.

The thing that has impressed me most, while listening for the past two days, is that you are obviously having difficulty in getting the medical care you need and are short of information about your own disability. In conversations here into the small hours of this morning, it seemed to me quite clear that you were all a little bit alarmed about what will happen to your breathing. It is noticeable in my country that, although there are very few new cases of polio, the number of people with polio who are using respirators is still steadily rising and there is no sign that the rate of rise is slowing down.

An Explanation for Respiratory Problems in Post-Polio Survivors

The reasons for this are really very simple. If you have complete or partial paralysis of the intrinsic muscles of breathing (the intercostals and the diaphragm), you have to use a lot of other muscles that are not normally used for quiet breathing.

Looking around, I see that a lot of you use your heads. You throw them back to increase the lift on the sternum. That is quite bad for the neck and the reason you often have neck pain. All these conscious acts of breathing, including tricks like frog breathing, don't continue when you are asleep.

It is perfectly true that there are one or two fascinating people who do, apparently, continue to frog breathe to a

limited extent during very light sleep, but by and large the accessory breathing muscles do not work during sleep.

There are good neurological reasons for this. The nerve wiring system for the extrinsic muscles comes down the spinal cord by a different route and from a slightly different part of the brain than the wiring system of the intrinsic muscles. When you go to sleep only the automatic respiratory center, which is the one that drives the intrinsic muscles, continues to generate regular breathing movements. If those muscles are not working properly because they are paralyzed or because the chest is distorted by scoliosis, then, inevitably you tend to under-ventilate during sleep.

Many of the standard lung function tests will not detect this because it does not show during your waking life. The diagram demonstrates this effect. It shows mean arterial carbon dioxide tension rises during sleep in four groups of people. Carbon dioxide tension in the arterial blood is a direct measurement of the amount of breathing. Normal people show sleep CO₂ rises of 10mm/Hg or less. Even those with chronic bronchitis (COPD) don't have a greater rise though levels are higher throughout. Compare this with the other two groups.

In effect, these people are climbing to 10,000 feet or more each night to sleep. They awake with a headache, their mental concentration deteriorates, and often they get daytime drowsiness, all often mistaken for signs of aging.

Getting to sleep is difficult, then they wake suddenly short of breath. This is commonly misdiagnosed as heart trouble. It is important to recognize these symptoms, because, given appropriate breathing aid at night, the future for you is in no way reduced.

"Polio Guts" - Another Medical Concern

Almost more than breathing in the

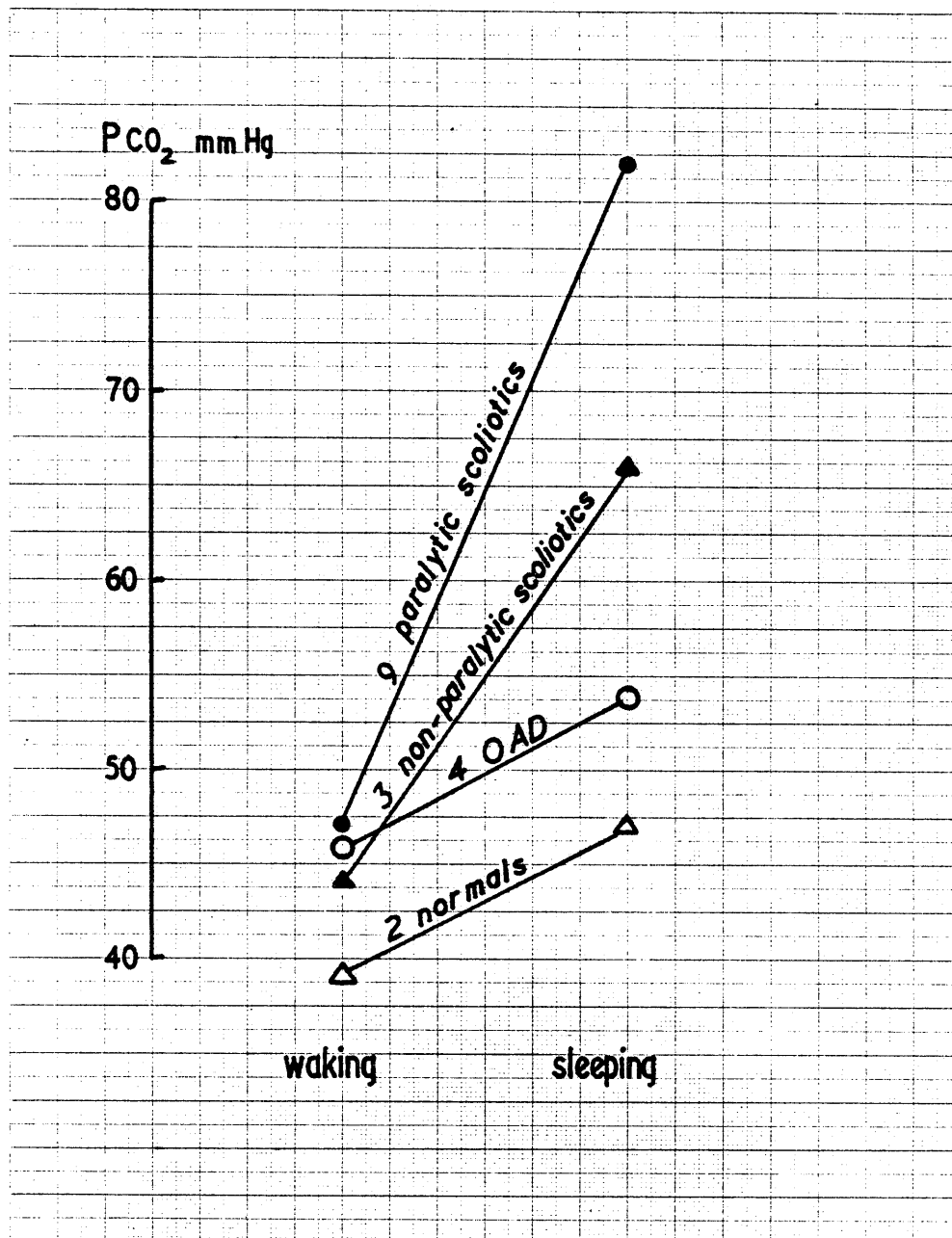
last two days, I have been asked about "polio guts." From top to bottom, the gastrointestinal tract has a hard time after bad polio. Swallowing can be difficult and needs great care. Hiatus hernia is almost universal following severe polio. A paralyzed diaphragm prevents belching. It is all too easy to swallow air if both swallowing and breathing are difficult. This happens particularly if you talk while eating and leads to "drum-tum." Treatment? Learn to swallow more carefully; don't talk with your mouth full. I could go on to talk about constipation, which is the other universal polio problem. I am supposed to run a respiratory unit, but I sometimes think it's more of a colon-clearing station!

The Future Model of Delivery of Health Care for Post-Polio

This leads me straight on to how you are going to continue to get the sort of medical care you need. It is quite obvious that in parts of this country you are getting along very well. Other areas do not seem to be so good, and I have heard some worrying stories these last few days.

As doctors, we can only learn by examining and treating many of you. A doctor needs 300 to 400 people with polio to look after and see fairly regularly to have enough clinical experience to know reliably what is going on. That is why I am a little bit worried about programs that would tag you onto regional spinal injury units.

There is a good deal of difference between the management of spinal injuries and the management of polio. Of course, one doctor can manage both, but only if he sees enough of each sort of patient to appreciate the differences. This is in no way a reflection on the competence of doctors; it is simply that, in order to be good, they have to see a lot of clinical material. You need transportation to take you long distances to special units caring for polio survivors.



Changes in Mean Arterial Carbon Dioxide Levels During Sleep
 (Note increase in slope in paralytic and non-paralytic people.)

The Ethical Issue

My final point is that there is no doubt that in this money-dominated age -- on both sides of the Atlantic -- you are very expensive. You would be cheaper dead. Adolf Hitler tried out the idea of eliminating inconvenient minorities and came rather badly unstuck. The only practical alternative is to do everything necessary to turn you into useful citizens. Is it worth it?

Many of my patients -- and I am calling them patients in the old-fashioned way -- say to me, "Doctor, if I had been told when I was still able-bodied that this disaster was going to befall me, I would have said I would rather be dead. However, now that it has happened, to my surprise, I find that my will to live is actually greater than it was before, because where previously I accepted survival as my right, I wanted something else to make my life amusing and entertaining and interesting and worthwhile. Now survival is in itself a satisfying challenge. I want to go on doing it."

That, to me, is the end of the discussion.

Our Obligation to You

Let us therefore look for a moment at the amount of knowledge that has come out of the work that has been done on polio. For example, methods of artificial respiration were developed for polio. It is as a result of artificial respiration that chest and heart surgery have become

possible, so you have actually contributed by what you have been through to a very great deal of knowledge that has benefited millions of others.

I think, therefore, that we have an absolute obligation to provide you with a rather special sort of service. I do think, actually, that you are rather special people, not because individually you are heroic or brave. I don't think you are. I don't think you had any option. Courage implies an alternative. To paraphrase an old poem, "The boy got off the burning deck as quickly as he could, as anyone with any sense naturally would."

You had to stay on the burning deck and get on with it. A few of you didn't and went under.

You are survivors selected by the law of the jungle, and I am quite certain that you will continue to survive in the future, whatever may be the little local difficulties in one country or another that may afflict you from time to time.

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CONSUMER PERSPECTIVE

Linda Bieniek

Communications Specialist,
Continental Illinois National Bank, Chicago, Illinois

Member, Board of Directors, Access Living, Chicago, Illinois

Contracted polio, 1956, and has severe
kyphoscoliosis and restricted respiratory function

A modern organizational approach will meet the complex challenges of tomorrow if we acknowledge the seriousness of present problems, believe they are resolvable, and individually accept responsibility for resolving them. Consumers with disabilities must be encouraged to demonstrate their individual abilities and respond to their personal life challenges. There is a need to collaborate, to negotiate, and to research and develop existing resources at all levels. Both in the education of and communication with health-care professionals, legislators, and the media, consumers with disabilities need to play an active role.

This positive approach recognizes the potential of the consumer, acknowledges the special problems, and provides a practical plan to incorporate consumers into a problem-solving coalition. It lays the ground for a needed organization with aggressive leadership, broad-based membership participation, and effective management principles.

* * * * *

A Polio Survivor's Organizational Formula for Success

When I am asked whether modern organizational approaches today meet the challenges of complex problems tomorrow, my reply is definitely yes.

I have always believed that, although many factors in life are out of our control, we often have more opportunities to effect changes than we realize. As consumers, many of us have already exceeded our projected life spans; we have demonstrated that we have the ability to make changes in our community as well as in our individual lives. In the past, we have worked as a team with health-care professionals and service providers to address many of our rehabilitation needs. During the past two days of this conference, we have convened with representatives from these sectors to gather information and recommend solutions to our present health-care and independent living problems. Having shared information, ideas, observations, and insights, we must continue working as a team and expand our network of support.

The magnitude of current consumer needs, combined with the instability of political, social, and economic trends, demands that we develop an effective organizational approach to meet the challenges, not only of expanding our resources and options, but also of safeguarding existing legislation and opportunities. We must design a cohesive action plan by proceeding with a thorough problem-solving process. We must gather information, identify our problems and needs, and determine our objectives. We must explore alternative methods of achieving our objectives, analyze their

advantages and disadvantages, and select appropriate tactics. We must act in an organized way, and finally we must evaluate our effectiveness.

The Concerns of the Polio Survivor

We are concerned. The television show, "60 Minutes," and the journal, Rehabilitation Gazette, report problems post-polio people are experiencing as they age. We have asked, "Does polio have long-range effects upon our general health which accelerate the aging process? Or do our problems stem primarily from other factors? Other conditions? Emotional stress? Our life styles?" We have concluded that, whether our problems are directly related to polio, to its side effects, or to a combination of factors, the issue still remains a matter for research and individual case assessment. Therefore, we must promote exchanges of information, individualized evaluations, and aggressive action plans which either address or eliminate the causes of our problems.

At this conference we discussed these issues, identified several health-care and independent living problems, and realized that many of them apply not only to people who have had polio, but also to those with other disabilities, and, in varying degrees, to some able-bodied people as well.

The Polio Survivor Meets the Challenge

As consumers, we can contribute to the mission of addressing complex consumer problems through group involvement in an organization or through individual support that demonstrates our self-sufficiency and self-image.

Historically, we have effected changes by collaborating with others. Because we have created independent lives for ourselves, we serve as role models for other consumers. Our primary responsibility and contribution lie in demon-

strating our individual abilities and effectively responding to our own life challenges. Since the strength of our consumer power base depends upon both the quality and quantity of individuals within that group, each of us must work to improve the quality of his or her own life.

Taking responsibility for challenges -- individual or organizational -- requires commitment. For that we need a spirit of determination, patience, and persistence. Effecting real change often requires a great deal of time, energy, and a variety of resources.

To achieve change we need cooperation and strong support networks, both on a personal and organizational level. We need to collaborate with traditional and modern organizations, and we need leaders and supporters who are highly qualified and reliable in fulfilling their responsibilities.

A Procedural Approach to Follow

We must identify our problems and assess our needs. What are our challenges, and what will be required to meet them? We have cited a variety of external and internal disturbances that include physical symptoms, environmental barriers, hostile attitudes, service difficulties, inadequate products and information, and, of utmost significance, emotional conditions.

We must determine our overall goals. Since we agree that we are primarily concerned about living independently, enhancing our life options, and maximizing our potentials, we need to develop realistic ways of fulfilling our personal needs, interests, and overall goals.

We must establish and prioritize our objectives and explore alternative methods of achieving them. We must ask ourselves, "What will each alternative cost us -- not only in dollars but also in time and energy? How do we benefit from it? What do we risk? What infor-

mation do we need to make a decision? Who could provide us with assistance?" Finally, we must determine whether we actually have any real choice given our objectives and circumstances.

We need an organized plan that is flexible, realistic, and includes tactics aimed at achieving specific objectives. From the beginning, plans must include procedures for designating certain individuals with decision-making responsibility and authority.

What Kinds of Barriers Do We Face?

Physical Problems. Our physical problems, which include shortness of breath and decreased alertness due to respiratory inadequacy, muscle weakness, organ dysfunction, and skeletal curvatures, result in limited mobility, unique pain, and dizziness. These problems may impair a person's ability to work and perform everyday tasks and exclude opportunities for social or recreational activities.

When addressing physical conditions, we know that we need also to identify patterns that may be either directly or indirectly related. For example, in the case of a post-polio person, we must assess the relationship of his symptoms to his life style and other external conditions. Because individuals may differ in many respects, a team approach for assessment is just as necessary and valuable now as it was in past years of polio rehabilitation.

Limited Resources. Often the difficulties we encounter stem from a lack of existing resources or inadequate utilization of existing ones. Readily available quality products and services which are affordable to consumers and professionals are urgently needed. Many of us have faced the obstacles encountered in trying to obtain respiratory equipment, repair services, and complete, current information.

Attitudinal and Environmental Barriers. We are especially frustrated with society's insensitivity, fears, and ignorance of disabilities and related needs. These attitudinal barriers manifest themselves in environmental conditions and the negative messages people convey to disabled consumers. For example, some environmental barriers (such as stairs, revolving doors, and high curbs), limit our accessibility to existing resources, while others, such as polluted air, threaten our general well-being. Negative responses, which degrade a disabled person because of his physical limitations, appearance, or dependency, may damage a person's self-esteem and create serious emotional insecurities.

Emotional Barriers. Emotional issues are usually complex and interrelated with other factors in our lives. Although often the key to resolving our problems, emotional issues are the ones which many people are most reluctant to address. Our sources of stress, which include all the external factors cited above, result in feelings of frustration, anxiety, and fear. When these feelings escalate, they may evolve into a sense of helplessness or hopelessness, which may be manifested through internal disturbances such as depression, anxiety, and insomnia.

Emotional frustrations combined with negative social responses may limit a person's potential more than any physical disability.

Both consumers and health-care professionals need to recognize that symptoms such as insomnia and anxiety seriously interfere with an individual's ability to fulfill his personal goals and live independently. We can take responsibility for our role in this problem-solving process by gaining self-awareness, exploring creative methods of dealing with our feelings, developing a network of personal support, and, when necessary, obtaining professional assistance.

The Objectives for our Action Plan

Create Networks of Support. We need to collaborate with others in a variety of ways. We must work with health-care professionals and service providers and seek the involvement of traditional organizations, such as the National Foundation - March of Dimes, the Easter Seal Foundation, and the Congress of Organizations of the Physically Handicapped (COPH), as well as more modern groups like the information referral networks and independent living centers. The magnitude of consumer needs demands that we make optimal use of existing local, regional, national, and international resources.

Organize with Leaders Among Consumers, Professionals, and Health-Care Organizations. We need an organizational structure with capable leadership. We need consumers who possess the art of promoting open communication with a variety of people who are result-oriented and effective in motivating others to act. We also need assistance from effective leaders like the dynamic organizers of this conference, people like Dr. Allen Goldberg, Gini Laurie, Dr. Henry Betts, who are committed to our efforts and are in positions of influence. We must work with representatives from many sectors of society to reach a broad spectrum of individuals and decision-makers.

We recognize that we now face not only the challenge of expanding our resources and options but also of safeguarding existing legislation and programs. For this, we need support from influential individuals and groups. Inner power struggles and competition between organizations must be overcome as we work together to use and develop resources.

Create Awareness by Education. To reach the broadest spectrum of people, we must educate the public through a variety of formats. Professionals also need to be encouraged to research and exchange information, and to increase

their understanding of the interrelatedness of our bodies, minds, and spirits, and of our own self-awareness. We can contribute to the process of understanding through health-related services -- institutional and community -- as they offer an opportunity to educate professionals about the practical and emotional issues which affect our lives.

Medical schools need to be encouraged to integrate an emphasis on the human aspects of patient care into their training programs. For example, Northwestern University now offers a "Patients' Perspectives" course, and at the University of California at Los Angeles, Norman Cousins developed courses in medical humanities.

To this end, we can attend association conferences and submit articles to journals such as the Journal of the American Medical Association and Hospitals.

School-based educational programs should be expanded to improve the attitudes of children and their teachers toward people with disabilities. This would also serve as preparation for any personal challenges they may one day encounter.

Become Part of the System. Our goal must be to become a part of the health-care organization by participating in policy, planning, and advisory positions on boards and committees. We need to encourage the use of patient ombudsmen to assist in resolving issues related to policies, procedures, communication, and service dissatisfaction.

Create Public Awareness by Independent Living. We need actively to promote the development and expansion of independent living centers. The majority of these centers work in two basic ways: they assist consumers by providing direct services which enable the client to live independently, and they work with other organizations and community leaders to develop resources and raise public awareness of issues related to the disabled.

Create Public Awareness by Communication. Communication needs to be strengthened with both public and private service providers. Economic conditions demand that we apply creativity in designing special insurance plans, vocational rehabilitation programs, and repair services for technical devices.

We consumers must also develop public awareness programs which provide realistic information about needs, values, and goals of persons with disabilities. For example, we must address the need for polio vaccinations; 400 new cases of polio in the United States in one year are unnecessary.

To change the public image of persons with disabilities, we must find ways to influence the media. Television, radio, and print mechanisms can be expanded to address our issues. For example, in Chicago, public service announcements have informed people about issues such as environmental barriers. This exposure can be increased to include prime time, closed circuit, and cable television. The media should be encouraged to include consumers with disabilities in commercials and regular programming segments as independent, assertive, productive people participating in daily activities. Special features could depict in a positive, realistic manner, void of sentimental and super-hero overtones, the challenges associated with independent living and developing one's potential in our society.

Create Awareness by Information Processing. With the volume of information and changes in our complex society, we need an accessible, centralized data base from which professionals and consumers alike can obtain information about subjects related to health and independent living. Computer technology needs to be adapted to meet this need for information by individuals and organizations.

Existing resources and programs need to be evaluated for their effectiveness. Operational problems which may impair effectiveness and efficiency need to be

identified. For example, the National Institute of Handicapped Research and other supporting organizations in the National Institutes of Health already possess some resources, and possibly the potential, to fill this need for a central registry of information. If not, we must find a voluntary organization to do so.

Work with the NASA Office of Technology Transfer could stimulate applications of space-age technology. We could also negotiate with such manufacturers as the auto industry to modify their manufacturing process during slow periods to produce devices and products for consumers with disabilities.

Engineering schools and academic university programs should be persuaded to apply their resources, not only to develop devices and gadgets needed by people with disabilities, but also to research cost-effective methods for their production and repair.

Our research must be documented and our programs evaluated to prove that they are cost- and quality-effective. We then should widely disseminate our positive demonstration and explain the key elements in our process that have led to success.

Obtain Support from Private and Public Sectors. As a long-range goal, we need to gain a strong support base from corporations and employers. We should seek guidance and expertise from business leaders who have succeeded in managing full-scale service operations, such as banks, realtors, insurance companies, and airlines.

By working with local organizations such as the YMCA and YWCA we can help expand opportunities for consumers with disabilities. For example, although we are told that exercising in the water is extremely valuable to our well-being, very few pools are accessible, affordable, and contain a suitable water temperature for our needs.

Private funding sources should be sought by approaching influential individuals and groups. We must make an effort to obtain assistance from people like the leaders of this conference and develop connections with people in social, political, and economic decision-making positions.

We should also solicit support from groups like the MacArthur Foundation which have available funds. The Carnegie Foundation claims that we are the most neglected minority. During this International Year of Disabled Persons, we must make aggressive plans to gain assistance from prominent, powerful organizations and individuals.

Personal Successful Demonstration of Meeting Challenges

I would like to summarize my own story of making personal changes. It shows, I think, that we can resolve complex problems through a decision-making process which combines reason and intuition.

I contracted polio at the age of five, and, as I grew, my weak back and chest muscles allowed my spine to curve, producing a common side effect of polio, known as scoliosis. Although my back was fused when I was a child, I still developed a severely curved spine which compressed my left lung and restricted my respiratory system.

During my adolescence, my breathing grew noticeably worse. Doctors told me they could not improve it because my bones had stopped growing and my respiratory system was permanently weakened from the muscle damage and pneumonias. I believed, however, that somewhere, someone must know of some solutions to help improve my breathing. I knew I needed to do further research to exhaust all possible alternatives, but I was extremely preoccupied with the challenges of attending college and preparing for independent living.

Shortly after I started to work full time, I realized that I gasped for breath when talking and walking. When I stood for even a short time, I experienced pain in my ribs, chest, and side. In those days, I did not realize how much energy was wasted by walking with a significant limp and striving to do more than my energy level allowed. I was unaware of the benefits of simple adjustments like a shoe lift.

Finally I took time from everyday commitments and explored my alternatives -- even further after confronting death during another bout of pneumonia. I realized that working full time was a struggle and that I needed to make some changes in my life.

I began my decision-making process by gathering information. I researched medical articles and consulted with a variety of health-care professionals around the country. In doing my research, I learned about my condition, the severity of my problems, and possible alternatives. I discovered that there were a few medical centers in the world where severe adult kyphoscoliosis (170°) had been treated successfully through a series of surgeries and traction. The treatment involved serious risks and a great deal of time and money. Little of the sparse documentation indicated that a severely scoliotic person's breathing improved from the process.

I desperately wanted to breathe better, to have more energy, and to straighten out my life. Both my reason and intuition convinced me that stabilizing my spine was the first step of that process. Although several internists diagnosed me as a poor surgical risk, I believed I would survive and benefit from the treatment if it were individualized to meet my personal needs. I decided to attempt surgical treatment and chose to undergo a series of surgeries and traction at the Twin Cities Scoliosis Center. There, I was actively involved in developing an individualized approach to suit my needs. I chose highly experienced

specialists and developed a personal support system of family, friends, relatives, college mentors, professional associates, and health-care personnel. As I underwent my treatment, I learned a great deal about myself and educated those treating me about my needs, condition, and capabilities. We used common sense and creativity in adapting technical devices, surgeries, and my physical environment to accommodate my physical and emotional needs.

Before my operations four years ago, I was about four and a half feet tall; my left hip was under my armpit; I had scarcely any neck; and the hump on my back was about three times its current size. I now stand seven inches taller and continue to grow healthier. After having straightened my spine, I have explored additional methods of developing my potential. My subsequent efforts to exercise, swim, eat nutritiously, resolve sources of frustration, and manage stress have helped to improve my respiratory difficulties. Whereas I previously retained high levels of carbon dioxide, my blood gases are now near normal levels and my vital lung capacity has improved slightly. More importantly, I feel better; my breathing is more relaxed, and I am more alert.

From this process I gained in self-awareness and developed many problem-solving skills. Emotionally, I am still healing; like the challenges we face as a consumer group, this process has involved years of frustration and anxiety, requiring the use of creativity and resourcefulness.

To begin to resolve some of my complex problems, I had first to acknowledge their seriousness, then believe that I had the ability to make changes, and finally take responsibility for the long but extremely worthwhile process of making

those changes. When I consulted with specialists, I identified not only my problems but also my goals. I told them what I want out of life, how I want to live and feel, and what interfered with my ability to make those goals a reality. I determined my priorities: to breathe better, to have more energy, and to straighten my spine.

I explored my alternatives by obtaining several professional opinions. I analyzed my options by weighing advantages and disadvantages and by applying my common sense and intuition. I made my decisions, took risks, and acted. I underwent and survived a series of operations, traction, and casts. When circumstances required, I adapted my responses to the best of my ability. As my plans proceeded, I developed a strong support system. I took responsibility not only for my decisions but also for participating in my care. In the process, I educated others -- the professionals treating me and the people supporting me. I worked with health-care professionals and service providers to use and develop existing resources, for example, braces and practical devices. I also learned a great deal about myself, my needs and limitations, my capabilities and goals.

By exploring additional ways of achieving my overall goals, I have developed my potential. I have evaluated the effectiveness of undergoing corrective treatment and my subsequent undertakings. I am better than I have ever been in my life; I'm healthier, more energetic, more relaxed and self-confident, and I am seven inches straighter.

Complex problems exist. Yet we have the power to effect changes. Making changes requires commitment. I encourage you to get to work and act now.

ORGANIZATION PERSPECTIVE

André Dessertine

Magistrate, Creteil, France

Former President, World Veterans Association

President, ADEP (Association d'Entraide des Polios Handicapés)

Invited guest of the U.S. Congress, 1976

Recipient of the Legion of Honor for service
to the disabled community of France

Contracted polio, 1962, in Paris and is paraplegic

The process of rehabilitation is global and must include the disabled person himself as the center of any care or service. The concept of disability is a relative notion that depends on one's ability compared with that of someone or something else.

The object of rehabilitation is to regain independence as individuals. This will not happen unless polio survivors have a certain number of rights -- the right to appropriate medical treatment, education, information, work, and housing. To achieve those rights, one must have the liberty to choose one's living arrangements and to travel. Polio survivors should not wait for the government, but join together with others to overcome present and future difficulties.

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[Mr. Dessertine apologized for speaking in French. His commentary was translated by Dr. Goldberg as follows. -- Ed.]

Reflecting on what has been said at this conference, I recognize that we have the same problems in France. Two thoughts come to me.

The Global Process of Rehabilitation

The first is that the process of rehabilitation is both global and continuous.

We have treatment for the active problems that continue until and through return to normal life. But during this time, the disabled person is not just an object of care. He is really the subject of a global rehabilitation process. It is necessary that the patient himself be totally involved in this process.

A disabled person may have attendants and all the assistance needed: doctors, nurses, psychologists, physiotherapists, social workers, information people, etc. But, it is the individual himself who is the center of that care, and it is that individual's responsibility to determine what that care should be.

That is why we, the polio disabled (of France), have had a leading role in the entire work for the disabled. It is necessary that we polios reflect upon our own problems. We must define the issues, and we must encourage research to find the solutions.

The Relative Concept of Disability

My second important thought is that the concept of disability is not an absolute concept but a relative one. A handicap is the result of conditions to be overcome by a person who is disabled in relation to something or someone else.

The Object of Rehabilitation

The object of rehabilitation is to regain our independence as individuals -- physical independence, psychological independence, economic independence, and social independence.

This will not happen unless we have a certain number of rights -- the right to appropriate medical treatment, the right to education, the right to information that is professional, the right to work, and the right to housing. To achieve these rights, one must have a certain liberty -- the liberty to choose one's own living arrangements and the liberty to travel throughout the rest of the city.

Solidarity for Action

For the future we need to develop the programs that will make it possible for us to accomplish these objectives.

We all know that there are difficulties to overcome, but we can affect the future. It is for us to realize what we desire to bring about with the help of all those who are not officially disabled. In an effort of solidarity, we must overcome the fact that people are not listening. If one gives economic ability to the disabled, one reduces the cost of their care remarkably.

During this visit, I have admired the tremendous achievement and independence that people with polio have realized. If it is financial aid that is needed for the development of your programs, you cannot wait for the government. You must overcome these difficulties yourselves by all means at your disposal. This conference will be an incentive, a stimulus to go out there and work together with others for your projects.

HEALTH-CARE PROVIDER

Mathew Lee, M.D.

Director, Department of Rehabilitation Medicine,
Goldwater Memorial Hospital, New York, New York

Centers that can serve as models of respiratory care for the rest of the country have been established on Franklin D. Roosevelt Island in New York City. The Howard A. Rusk Respiratory Rehabilitation Center at Goldwater Memorial Hospital was founded and dedicated in 1978 to provide excellence in respiratory rehabilitation. Its areas of responsibility include clinical care, clinical research, and education. The Regional Respiratory Service of Goldwater has continued to expand and improve upon its services to those with disabling respiratory conditions of all kinds.

* * * * *

Colleagues for a common cause! I have a few comments, and they are entitled, "Dreams Come True." As I winged in this morning over Lake Michigan, I was thinking about the time I flew in ten years ago, almost to the exact day, with Harriet Bell to attend a meeting of the American Hospital Association for Chronic Care. The meeting was entitled "Winds of Change," and Harriet gave a wonderful presentation.

Had you in the audience ever thought ten years ago that you would be flying in an airplane to Chicago for this meeting? There has been change, hasn't there?

Again, after a decade, I am here with Harriet Bell. And this time specifically for a polio conference. Changes appear quite slowly at times, but still this is progress.

Louis Pasteur stated that chance fa-

vors the prepared mind. What do these words mean? Now that is what you people are doing here. You are gathering statistics, and you are exchanging views so that we leave less to chance, perhaps.

Franklin Delano Roosevelt Island

Do you know that we have an island? A few years ago, Welfare Island in New York City was named the Franklin Delano Roosevelt Island. So we do have an island, and just a few months ago we had a beautiful day that was proclaimed Franklin D. Roosevelt Day for the International Year of Disabled Persons. Mayor Koch came and issued a proclamation, and we had a full day of fun, activities, games, and fellowship to highlight our cause. Curtis Roosevelt was there to honor us and speak of his grandfather's disability, or rather ability, despite his paraplegia. Yesterday, before I left the hospital, I received word that Franklin D. Roosevelt Park, which is now barren acres on the Roosevelt Island, will be greened.

The United Nations and the City of New York, together with other organizations, will make this a beautiful park in memory of our late president who did so much to draw attention to poliomyelitis. Facilities will provide complete accessibility.

We hope not only to address ourselves to polio but to all who are disabled and aged, and need help. We will build on this park a dream, a park for the blind so that they may smell flowers, a park for all citizens of this country and this world, as

a beacon.

In 1978, we established the Howard A. Rusk Respiratory Rehabilitation Center at Goldwater Memorial Hospital. The purpose was to develop a center of excellence for rehabilitation of respiratory patients. It has a triad of responsibilities: clinical care, clinical research, and education.

In 1955, the Regional Respiratory Service, later named National Foundation of Infantile Paralysis, and the City of New York established a ward at Goldwater Memorial Hospital to care for severely disabled polio patients. Since then, the Service has grown to 37 beds and serves an outpatient population of 100.

Originally established for the treatment of respiratory problems resulting from poliomyelitis, the Service has gradually added the treatment of chronic, crippling respiratory conditions arising

from other diagnoses. One-day evaluations are given which encompass total evaluation: cardiopulmonary testing, wheelchair maintenance, respiratory aid evaluations, and other required services. Its reputation as a specialized clinical center has been constantly enhanced, and now it is addressing itself to other crippling conditions.

I hope that this will be part of your dreams here, too, to develop these centers of excellence so that we can gather and share information in order to provide better care for all of you.

Let me leave you with just one thought, that we must develop alternative patterns of care which basically must be within the economic framework of our society. This is the responsibility of each of us. We must each be the eternal optimist. So join with me to reach for the stars, and failing to touch them, we can still gain the universe!

CONSUMER PERSPECTIVE

Judy Heumann

Director, Center for Independent Living, Berkeley, California

Contracted polio and is paraplegic

In comparison with the last decade of political accomplishments by disabled consumers, 1981 has been a year of fear and retreat. Serious attempts have been made to destroy the political advantages recently won by disabled consumers. The current emphasis on "local option" is likely to result in nonuniform conditions for disabled people and a decline in services.

The disabled consumer, especially those privileged to attend this conference, must take on a leadership advocacy role. The conference provides a forum for discussion of issues and joining with leaders who will accept the responsibility for counteracting current legislative trends.

* * * * *

I have some major concerns about what is going on right now within this country. We have moved a little bit off the topic of polio exclusively; we need to look broadly at some of the political ramifications of current events.

A Decade of Political Accomplishment

André Dessertine talked about our need to have rights, the right to education, housing, and transportation. It made me reflect that over the last ten years, major advances have been made in this country through the struggles of many of us in this room and other disabled people

throughout the United States. I talk specifically about the Education for All Handicapped Children's Act, Public Law 94142, section 504 of the Rehabilitation Act, and the Rehabilitation Act, in general, including Title VII of the independent living program provisions.

Now is No Time for Complacency

I think we do ourselves a disservice if we continue to pat ourselves on the back and say that things are rosy. In the reality of life, a lot of us have become very stymied and frightened. This trend is largely due to the Administration's attacks that have been going on since January 1981. There has been continual discussion about how the United States does not have enough money, so we all have to take a little bit less.

We Create our Image by our Action or Inaction

As one of a number of people who really never have had enough, I have a lot of difficulty determining why I should take less when I have never had my equal share. If we continue to buy into the Administration's line that we have to take less when we haven't had enough, we are fooling ourselves. Because we are not an active minority in this country, they consider us to be an unvocal population of whom they need to take little heed. That is our fault!

A Call for Active, Responsible Self-Advocacy

We must make sure that when we leave this meeting today we are determined to work and write to the congressmen to let them know about the concerns that were discussed at this conference. We are not looking only at the issue of polio, respiration, and other problems which for us are very immediate and life-threatening. We must broaden our scope to the whole issue of civil rights for disabled people.

When I think about Mayor Koch and the dedication of Roosevelt Island, I also think about the City of New York being one of the biggest opponents to accessible transportation. The City of New York has put a lot of money into violating the federal law and has encouraged the federal government to repeal Section 504, Transportation Regulation. If we repeal Regulation 504 that deals with accessible transportation, we are taking away the rights of disabled people to be able to go out and get employed.

When I realize the government is trying to cut back money for the Rehabilitation Act, discussing the repeal of Public Law 94192, allowing everything that we fought for to go back to the states for local option, I feel we are being thrown back into the "pot." If local government decides that disabled people have a right to live like equal human beings, we think it is wonderful. But if that same district decides that disabled people are not a priority, that is just the way it is going to be. I don't think we can allow that to happen.

We Must Take the Leadership Role

We are very lucky to be in this room today. All of us that are here are the "haves" of this country; we are not the "have-nots." We do not have as much as we should have, but we certainly have a lot more than many other people who are not here. It is an incorrect position to pat

ourselves on the back when we know how many kids are still not in school, how many kids are still not receiving an appropriate education, and how many disabled people are not working -- not because they do not want to work, but because the Department of Rehabilitation does not have enough money to provide services. People who have been trained cannot go to work because they cannot afford to pay for transportation, or they do not have money for attendant care, or they do not have money to maintain a wheelchair, or whatever the innumerable issues are that we could talk about now.

This Conference and our Future Responsibilities

To leave this conference thinking that we have accomplished everything we want would, in my opinion, mean that the conference is a failure. This conference has begun to allow us to discuss and articulate many issues and has gathered together many of us who are very strong advocates.

As advocates, we lose our effectiveness if we feel that we have risen to a point where we no longer have anything to do. In reality, we have more to do now than we had ten years ago, because ten years ago we didn't have any of these legislative pieces. We fought to get them, and now they are being whipped away from us. There is something wrong going on when this Administration believes it can so easily take away rights that people have fought for so hard. It is our responsibility to make sure that we go back and talk to other disabled people, to other parents, and to other professionals. In 1982, when elections come up, legislators who voted against us must realize that we know how they voted and don't appreciate or approve of the reasons why they voted in that way.

I cannot listen to somebody explaining to me why regulations concerning disability are being repealed. To me it means that those people who have money

or privilege do not need the legislation that most of us in the room are acquainted with, and which millions of other disabled people in this country will neither know about nor benefit from.

I hope the questions that we raise will get really provocative, and I hope we get off our duffs. I hope we recognize the responsibility to stop accepting what is going on right now.

KEYNOTE ADDRESS

C. Everett Koop, M.D.

Deputy Assistant Secretary for Health,
Department of Health and Human Services

Surgeon General Designee of the United States, Washington, D.C.

I do want to thank the organizers and the sponsors of this meeting for inviting me to participate. I consider it to be truly an honor and a privilege to be among this distinguished company. Dr. Goldberg will be having the last word today, as well he should, and I want to take a moment just to congratulate him and his colleagues on the Planning Committee for bringing together in a coherent fashion a very complex experience in the history of medicine and health care.

In the few moments I have to share with you this afternoon, I want to take a look at what we have learned from the polio experience and see how it contributes to the shaping of health policy in this country. We are extremely fortunate to be able to draw upon the knowledge of so many dedicated people. Not just our own citizens, but people like André Dessertine from France, Audrey King and Dr. Joseph Kaufert from Canada, Adolph Ratzka and his colleagues from Scandinavia, and Dr. Geoffrey Spencer who pioneered in the field of respiratory care in Great Britain.

We have every reason to be optimistic about how we care for disabled persons in the future, since we will be building upon such a strong foundation of knowledge, experience, and compassion.

I have had a good deal of experience as a pediatric surgeon dealing with many forms of respiratory distress in infants. But let me say right at the outset that I do not want to repeat the information you already have received in the course of

this three-day meeting. As many participants have already noted, the costs of maintaining respirator-dependent infants in a hospital setting are astronomical, and they are not leveling off.

These are things that you know from your own experience in treating infants, young people, adults, and victims of paralytic polio. The issues that you are wrestling with do not exist in a vacuum, and this you also understand well.

I believe my best contribution at this meeting can be to help illustrate what the federal government's perception of this issue may be, how it relates to the broader challenge of defining the federal role in the whole area of disability, and what the public's expectations and responsibilities might reasonably be.

In the 1930s it really was one man, a federal official, the President of the United States, FDR, who succeeded in capturing public attention and focusing it upon paralytic polio, but that is as far as the government went.

It was an era before the establishing of the National Institutes of Health, before the government developed the mechanism it has today to support individual researchers here and around the world. And, as terrible a question as it may seem, we have to stop and ask ourselves, "What would have been the history of the fight against polio if President Roosevelt had been able-bodied and not dependent upon a wheelchair and crutches?" I say it

is a terrible question since it poses for us the constant sense of uneasiness we have about the basic instincts of mankind.

Joseph Wood Krutch, the naturalist and critic, a marvelous writer, described people as he saw them in his book, Human Nature and the Human Condition. "What some of us tend to call the 'human being' first came into recognizable existence about the year 475 B.C. and began to disappear about 75 years ago."

This is a very wry way of saying what we see ourselves to be. But it leads to the very serious question of whether and how you can convince people to follow their own highest instincts without an awful lot of effort.

Let me interrupt myself here and say that I do not have the slightest doubt that we, as a people, can do this and can do it far better than we ever have done it before.

Franklin Roosevelt had that gift of persuasion, and the beneficiaries, many of them, are here today. His example is particularly appropriate because it also demonstrates that government may not necessarily be the key to the solution of our problems. One person with a sense of purpose and masses of people following their own best instincts as private individuals may be far more important.

The March of Dimes and the National Easter Seal Society are among your co-sponsors here today. They and many other private volunteer organizations provide an outlet for action that cannot be underestimated.

About a month ago, President Reagan met with a number of representatives from private volunteer groups and said to them, "I have a distinct feeling, and have had for a long time, that we have as a people drifted too far away from the volunteerism that so characterized our country for so many years."

He asked the representatives -- and

through them he asked this nation -- to rediscover that vast human strength that has been part of our social fabric since this nation was founded. I would suggest that the significance of the voluntary effort throughout the polio experience needs to be addressed. It was substantial. But even at that, it may prove to be not a completely adequate model for today's requirements.

We have come to a stage in our history when the federal government has become overburdened with a great variety of social and human services. It does the obvious thing. It passes the costs on to the taxpayer or, at least, that has been the approach up until now.

Today we are wrestling with the issue of appropriate balance, and we are taking all the steps necessary to remove the federal government from as many activities for which it may no longer be the most appropriate or the most cost-effective agent.

We are taking some of these burdens away, but now, instead of passing the costs back to the taxpayer, we are passing the programs themselves back to the people best suited to handle them. Sometimes these are state and local governments, but very often they are private voluntary organizations.

That is the strong belief of President Reagan, and I think he is right. This is the context of federal planning, as we turn to the challenges of this decade, and we certainly are not lacking for challenges of every sort. Let me share some of them with you and suggest what our response may be.

As you are no doubt aware, this country has been making steady progress in the improvement of health status. For the past 20 years, there has been a steady decline in the age-adjusted mortality rates among four of the five leading causes of death: heart disease, stroke, accidents, influenza, and pneumonia.

The story with regard to cancer, the second leading cause of death in this country, is mixed. For persons under the age of 45, the mortality rate has dropped about 33%. We have also had dramatic success with certain cancers that affect children, particularly leukemia, Hodgkin's Disease, and so on. On the other hand, there have been increases in the mortality rate for cancers in certain sites, such as the breast, colon, pancreas, and respiratory system.

In other ways, too, we have an idea that our national approach to preventing premature death may be succeeding even though the record may be mixed. For example, our life expectancy has been increasing. It is now 73.6 years for a male born today, but that is an average. There is a wide discrepancy; for example, the life expectancy for a black male is about 65 years, and for a white female, it is about 78 years.

Similarly our infant mortality rates have come down, as should be the case in an advanced industrial society such as ours. We are at about 12.5 infant deaths for 1,000 live births. Here again, there are tremendous racial variations, with black infant mortalities at about twice the national average, white Americans at just about the national average, and Chinese-Americans at about one-half the national average.

Now, that is an impressive record for this country. It is a record we should want to improve in the years ahead, and I feel sure that we will.

The reason I have gone into all these mortality statistics with you is that they mask a very challenging picture of morbidity and disability. In a typical year, the Center for Disease Control will be called in to investigate some 1,700 outbreaks of infectious diseases. The number of polio cases, fortunately, as you know, amounts to only a handful, but we are experiencing a steady rise in the number of cases of sexually transmitted diseases such as gonorrhea, syphilis, and herpes

simplex. Over two million new cases a year cost this country more than one billion dollars just in surveillance, diagnosis, and treatment.

Influenza and pneumonia still rank among the ten leading causes of death and are our most persistent infectious diseases generally. Each year we try to prepare ourselves with the right vaccines in the right quantities for an anticipated outbreak of influenza. Our guess may be right, or it may be wrong. There are many strains we know about, and there are no doubt many more strains we are going to know about and may not be adequately prepared to fight.

We have a somewhat similar situation with penicillin-resistant strains of gonorrheal bacteria that are beginning to appear. In addition, what has become an especially worrisome problem is the rise in the incidence of those highly communicable diseases, the infections picked up in hospitals and other treatment facilities. These also tend to be drug-resistant, since they have been growing in a warm and cozy treatment environment.

Hence, parallel with our victories in preventing premature deaths is a murky picture of success and failure concerning morbidity.

I have gone into all this because, although the disabled and their future is my highest priority in the Department of Health and Human Services, you have to know the way the rest of my colleagues view the health problems in this country as a whole so that you see where you fit into their concerns.

To get some perspective on the slow but steady rise in the numbers of Americans who are disabled each year, we can look back to 1969 when 11.6% of the population were disabled. That is, nearly 23 million people were limited in some way from carrying out the normal activities of their age group and sex. By 1973, the total had risen to 13.3% of the population, or 28 million. In 1978, the trend

continued with 13.6% of the population limited or disabled in some way, slightly more than 30 million people. The trend seems to be continuing still.

The reason that I stress morbidity is that we can assume today that one in every seven Americans is disabled, limited in some way from living a life that is normal for his or her own age group.

What we have, then, is a population in which an ever increasing percentage is considered to be either temporarily or permanently disabled. While they no longer appear among the mortality statistics, they may be among the morbidity and disability statistics. These are:

Persons who have not died from heart disease but who are among the five million or so who are limited in what they can do for the rest of their lives;

Persons who were not victims of paralytic polio but who nevertheless are among the nation's nearly five million who suffer from impairments of the back, spine, shoulders, and upper and lower extremities;

Persons who have not died of respiratory cancer but are among the three to four million who live with disabling and chronic bronchitis, asthma, emphysema, and other respiratory conditions; and

Persons who have managed to take advantage of additional years of life but do so among the six million or so who suffer from arthritis, rheumatism, or other musculoskeletal disorders.

To date we have a mixed history reflecting our ability as a wealthy and compassionate nation to deal with the range of disabling conditions among so many millions of people. In addition, we are only now beginning to measure in hard dollars the cost of these disabling conditions upon society as a whole. Let me

give you a few figures.

From the data collected in the National Health Interview Survey, we have been able to estimate the economic burden of disability for 1977, the latest year for which we have figures. A total of 496 million days were reported as lost from work because of acute or chronic conditions. The total earnings lost by people missing from work for these conditions amounted to \$25.6 billion. For those people, somebody or some agency, had to make up the lost income. Maybe it was workmen's compensation or insurance, or a relative or friend. It may have been a charitable organization. Or it may simply have been lost.

Except for the last outcome, we have to assume that there is a transfer of that money from one kind of activity account to the other, the payment of foregone income. That would be a very simple bookkeeping matter, if it did not involve \$25.6 billion. That is one kind of economic burden we have to face.

A different kind of burden is that of lost productivity. In 1977, again according to the Labor Department, there were 2.8 million people who could not work at all because of illness or disability. These people are different from those who usually work but lose days because of illness, the ones who missed \$25.6 billion in income.

We are now talking about people who are not in the work force at all, 2.8 million of them. It is estimated that the loss of their productivity in 1977 cost our country an additional \$23 billion. In addition, economists have estimated the value of keeping house. If you had to go out and hire somebody to do it for you, the cost would range from \$9,700 a year for a woman in her late twenties to \$5,500 for a woman above the age of 65. That is in 1977 dollars. During that year, 1.3 million work-days were lost as a result of disabling conditions among housekeepers, for another total cost of \$6.3 billion.

If you add up these three figures -- the losses among persons who are employed but miss workdays, the losses from people who are not employed because of chronic illness or disability, and the losses among ill or disabled homemakers -- we arrive at the estimate for 1977 of an economic burden of illness in this country of \$54.9 billion, a sizable loss for any society.

The major cause of these losses is heart disease. Accidents are the second; all cancers, the third; and strokes, the fourth.

These kinds of estimates have been developed for the past several years by a number of economists and statisticians. The figures I am relying on are drawn from the work of Dorothy Rice, who is the Director of the National Center for Health Statistics and one of the pioneers in the area of health economics.

This kind of information is especially useful in times of fiscal and budgetary austerity. We are in one of those periods now. So we have to match those kinds of data with the knowledge and experience of the disabled person, in other words, with information from meetings such as this. From that mix, along with other ingredients, we should begin to see the outlines of a new and effective national policy for meeting the challenge of chronic illness and disability in the America of the 1980s and 1990s.

For example, I think all of us can agree on -- or at least agree to take seriously -- several propositions.

First, it is unwise to approach this problem on a disease-by-disease or disability-by-disability basis. As the statistics indicate, many people suffer from multiple disease or disability conditions. Also, if we followed that approach, each of us would have to say that every condition required 100% of our money and effort. There are relationships that have to be weighed, including the relationship of the condition to its total effect upon

society and the economy.

I might add that the National Institutes of Health have embarked on this kind of research planning. They are looking at problems such as nutrition as matters to be studied by several or even all of their Institutes. It is a serious and highly valuable effort to break down the barriers between Institutes, which is an organizational problem, and barriers between researchers in different phases of disease and disabling conditions research, which is a conceptual problem.

Second, we must ascertain, as best we can, who pays what costs for chronic illness and disability and if that is a fair expression of how we as a society want the burden to be shared. In many cases we seem content to let the burden fall most heavily upon those people and their families who are directly affected by the disability.

Relative to the significance of their experience to the total health and well-being of society, that would now seem to be an obsolete answer. On the other hand, not all persons in society can contribute a share of wealth; not all pay taxes; not everyone can make charitable donations; not everyone can contribute in kind, if not in dollars.

In our type of society, where participation in social and political processes has a very high value, this is an important issue. It is, of course, the classic debate of rights versus responsibilities: I have a right to be left alone, to determine how I want to live as long as I don't injure anyone in the process, but I also have the responsibility to somehow help others who would like to exercise that same right but do not have the wherewithal to do so.

Again, if I may invoke the current economic condition, we need to assure ourselves that our policies do not have a disproportionate impact upon the disabled and their families. So far, government has made an attempt to be fair, and many private organizations and professions have

worked to keep government honest in that regard, but the guarantee of fairness is everyone's task, public and private.

Third, we have come a long way in our understanding of the role to be played by institutions of care. It is a much smaller role than at one time was imagined. The swing away from institutionalization is gaining interest and momentum and makes a lot of sense for a lot of people, but I would hope that we would begin to give deeper thought to what the alternatives are to institutionalization.

Item: It is not enough to work toward moving respirator-dependent infants from our intensive care pediatric facilities. We need to do more work with parents and neighborhood groups and public services to make sure that the alternative for the infant is not an environment of danger, life-threatening, or uncaring.

Item: The issue of alternatives is also becoming a problem among the elderly. We are aware that some women homemakers in their late sixties and seventies are given inpatient care for a period of time, but then are sent back to the community, to their homes, where there may be no one to care for them. This is the phenomenon of the aged parent who has outlived his or her children, who has survived heart disease or stroke through the miracle of medicine, but will not survive the ordinary stresses of living at home without additional care.

Item: As I illustrated with the slowly rising trend line of the number of disabled persons in our society, there are more and more people who have known independent living and who have experienced a particular quality of life pleasing to them for whom both independence and quality may have been erased by illness or disability. Or so it might seem, but I cannot accept that as a given proposition.

In this instance, I think society has to rededicate itself to the rights of those who are handicapped. And I say "society," not just "government" or any particular

segment or sector of society. We cannot replace lost limbs or damaged organs. We may not be able to reverse mental retardation or correct all birth defects, but we can try to make sure that every person with these or other conditions is encouraged to take part to the fullest extent in our nation's way of life. With that encouragement goes society's responsibility to protect those individuals as they pursue their legitimate personal and family goals.

I think that has to be part of the deinstitutionalization movement. What good is it if we reduce the chances of a person being unfairly institutionalized only to discover that the walls are just as high outside the community? We have our work cut out for us as far as that is concerned.

Finally, the disabled community -- persons suffering from chronic disease conditions as well as from disabilities -- this varied community has had a rather high level of participation in policy development and program implementation over the years.

Sometimes the disabled themselves are involved, which has been the case with polio victims, for example, or they are vigorously represented by surrogates and advocates. We are just beginning to understand the importance of this kind of participation.

As the median age of Americans continues to rise, the median age of disabled people is rising, too. We can expect, therefore, to hear from a new and more complex constituency in the future, older people who are disabled and suffer from a chronic condition, yet demand, as is their right, to participate fully in the decisions of their community and of society in general.

I think society itself, as well as each organization that represents the disabled, needs to ask itself whether or not it is equipped to grow with these changes and to accept and carry out the responsibili-

ties of the future. It is one thing to extol the virtues of our participatory democracy. It is another thing to carry them out. We ought to do both of these things just as well as we can -- now and for the decades to come.

As you can tell, I did not come here this afternoon with a briefcase full of answers, nor did I come with a particular focus of the polio experience. That is an invaluable experience, and it will contribute to how we work in the future on behalf of all of our citizens with whatever chronic illnesses and disabilities they may have. But I did come here today to share with you several of the questions that we all need to study and answer: How do we maintain our moral and ethical commitments with a redrawn and constrained federal presence? How do we guarantee equity and compassion in the midst of a growing complexity of information and issues? How do we change the traditional behavior of individuals and institutions toward the disabled in light of the growing community of such persons? Finally, how do we bring back into balance the sharing of responsibilities and costs among both the public and the pri-

vate sectors, the individual, and the community?

I know that you individually and collectively will be putting your minds to the answers to these questions. I want you to know that they are answers with a very high priority for my own personal life and for everything that I will be doing for the next four years in the Department of Health and Human Services.

I am not permitted to depart very much as a government representative from the things that I have planned to say, but I would like to depart just for a moment and tell you that it is my outstanding priority to work in such a way for the disabled in this country that, by the time I leave Washington, there will be established for the disabled a Magna Carta which gives them the opportunities I think they deserve.

In closing, let me once again extend my congratulations to the planners of this meeting. You will never know how important a cog this is in the whole machine, and thank you again for letting me join you. I look forward to seeing a summary of all that has taken place.

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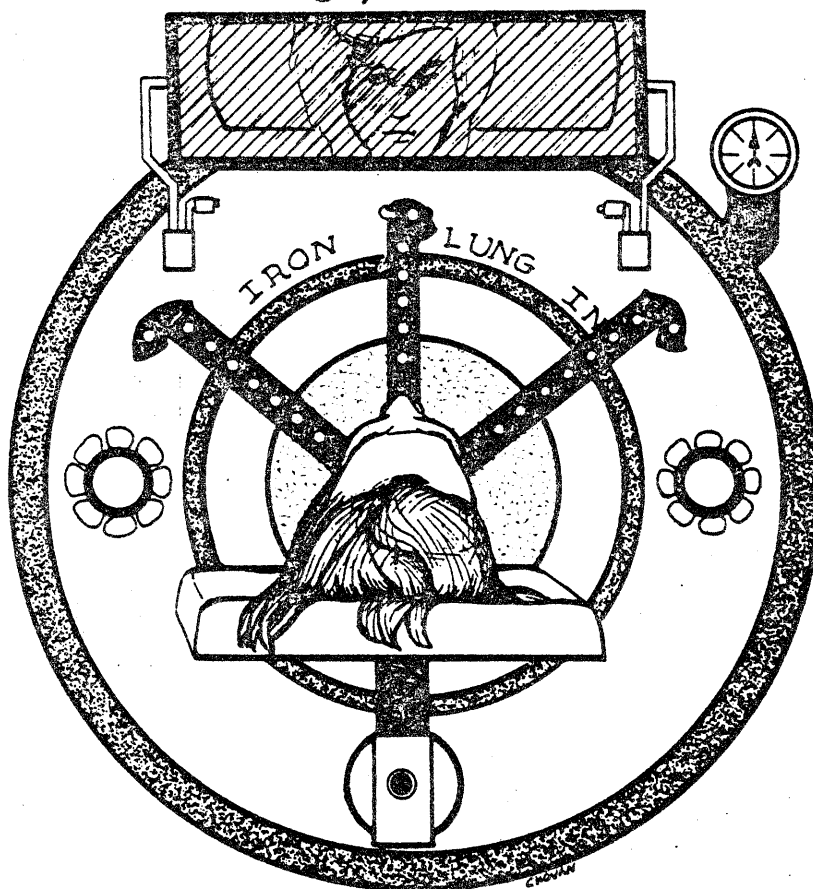
APPENDIX A

PROGRAM DOCUMENTS

What Ever Happened to the Polio Patient ?

* OCTOBER 14-16, 1981

Chicago, Illinois



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INTERNATIONAL SYMPOSIUM ON RESPIRATORY REHABILITATION AND POST-POLIO AGING PROBLEMS

In the fifties, the world faced and met the challenge of a health-care crisis created by polio. People, working together, creating and applying technology and organizations, met needs.

In the eighties, we are again challenged. Today's (and tomorrow's) crisis results from the need to apply available knowledge and resources to improve the health of the polio survivors. As before, the successful efforts will benefit many others with respiratory and non-respiratory problems.

On October 14 and 15, we will celebrate the International Year of Disabled Persons by demonstrating our concern at a working symposium with invited guests and participants. After two days of closed session, we will open our symposium on October 16 to all interested people and the public. We will demonstrate a process of analysis and synthesis -- to create opportunities for others to approach health-care delivery issues with workable solutions.

PLANNING COMMITTEE

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Hosts

Rehabilitation Institute of Chicago
Rehabilitation Gazette

Sponsors

National Foundation - March of Dimes
National Easter Seal Society
Children's Memorial Hospital Department of Anesthesia
Northwestern University Department of Anesthesia
LIFECARE Services, Inc.

Contributors

President's Committee on Employment of the Handicapped
Royal Canadian Legion, Alberta Division
Class of 1956, Indiana School of Medicine
Care for Life
Polio Survivors Association
Congress of Organizations of the Physically Handicapped
Thompson Respirator Products

Location

Americana Congress Hotel
520 South Michigan Ave.
Chicago, Illinois
(312) 427-3800

PROGRAM OBJECTIVES

The attendee will be able to understand the current status of polio survivors with and without respiratory insufficiency (inadequate respiratory function to permit the fullest potential of health).

The attendee will:

- a. Study the clinical presentation of polio in the past and present time.
- b. Analyze the health-care delivery given to polio survivors and determine unmet needs.

The attendee will be able to analyze and evaluate a major health-care crisis and effectively plan actions to meet it.

The attendee will:

- a. Learn the historic reasons for the successful response at this time.
- b. Analyze the current elements/forces/interests that must be considered today for a successful approach to meet the needs of polio survivors.

The attendee will be able to design a multidimensional approach to a health-care issue in order to optimally utilize all human, technological, and environmental resources.

The attendee will:

- a. Demonstrate the value of multiple solutions to meet the needs of polio survivors:
 - institutional care
 - home care
 - alternatives to home care
 - group therapy
- b. Develop a process of multidiscipline team building to effectively apply all involved and knowledgeable people who can contribute to the success of the approach.

The attendee will be able to understand the relevance of the current situation of polio survivors to those of other individuals with other related medical problems who today have been the beneficiaries of what was accomplished for and by polio survivors.

The attendee will:

- a. Understand that the respiratory rehabilitation techniques and organizations can benefit children and adults with spinal cord injury, multiple sclerosis, muscular dystrophy, etc.
- b. Understand that a well-designed cost-effective and personal solution for one group can benefit many others.

WHAT EVER HAPPENED TO THE POLIO PATIENT?

Americana Congress Hotel
Chicago, Illinois
October 14-16, 1981

Tuesday, October 13, 1981

7:00p Registration
Get-together

Rehabilitation Gazette

Wednesday, October 14, 1981

8:00a Registration
Continental Breakfast

SESSION I

THE PAST: THE EXPERIENCES OF THE POLIO PATIENT

9:00a **Opening Remarks**

Henry B. Betts, M.D.
Chairman, Department of Rehabilitation Medicine,
Northwestern University Medical School
Vice-President and Medical Director,
Rehabilitation Institute of Chicago
Chicago, Illinois

Gini Laurie
Co-editor and Publisher
Rehabilitation Gazette
St. Louis, Missouri

9:10a **Definition and Scope of the Crisis**

Allen I. Goldberg, M.D., Moderator
Medical Director, Division of Respiratory Care,
Department of Anesthesia, Children's Memorial Hospital
Assistant Professor of Anesthesia and Pediatrics,
Northwestern University Medical School
Chicago, Illinois

9:15a **Health-Care Delivery Perspective**

David Dickinson, M.D.
Chief, Clinical Affairs
University of Michigan Hospital
Ann Arbor, Michigan

9:35a **Reactor**

Augusta Alba, M.D.
Director, Howard A. Rusk Respiratory Rehabilitation Center
Associate Director, Goldwater Memorial Hospital
Associate Professor of Neurology and Rehabilitation Medicine
New York University School of Medicine
New York, New York

9:45a **Consumer Perspective**

Ronald Doneff, M.D.
Hobart, Indiana

10:05a **Reactor**

Jack Genskow, Ph.D.
Professor of Rehabilitation, Sangamon State University
Springfield, Illinois

10:15a **Organizational Perspective**

André Dessertine
President, Association d'Entraide des Polios Handicapés (ADEP)
Paris, France

10:35a **Reactor**

Audrey J. King, M.A.
Ontario Crippled Children's Centre
Toronto, Ontario, Canada

10:45a **Coffee**

11:15a **What Factors Led to a Successful Approach
to Meeting the Needs of Polio Patients?**

Audience Participation with panel of invited guests, including:

Adolph D. Ratzka
Stockholm, Sweden
Rev. Patrick Lewis, C.S.S.P.
San Francisco, California

1:00p **Lunch**

SESSION II

THE PRESENT: A CRISIS? THE NEED TO DEVELOP COST-EFFECTIVE AND PERSONAL SERVICES FOR POLIO SURVIVORS

Ernest W. Johnson, M.D., Moderator
Professor and Chairman, Department of Physical Medicine
Ohio State University Hospitals
Columbus, Ohio

2:15p **Health-Care Perspective**

Alice Nolan, R.N., M.A.
Research Associate
Goldwater Memorial Hospital
New York, New York

2:35p **Reactor**

Ann A. Bailey, M.D.
Staff Physician
Roosevelt-Warm Springs Institute for Rehabilitation
Warm Springs, Georgia

2:45p **Consumer Perspective**

Margaret C. Pfrommer
Consumer Advocate and Research Associate
Northwestern University Rehabilitation Engineering Program,
Department of Orthopaedic Surgery
Northwestern University Medical School
President
Illinois Congress of Organizations of the Physically Handicapped
Chicago, Illinois

3:05p **Reactor**

August W. Christmann
Executive Director
Illinois Congress of Organizations of the Physically Handicapped
Chicago, Illinois

3:15p **Organization Perspective**

James C. Campbell, President
LIFECARE Services, Inc.
Boulder, Colorado

3:35p **Reactor**

André Dessertine
President, Association d'Entraide des Polios Handicapés (ADEP)
Paris, France

3:45p **Coffee**

4:15p **What Factors Today Must be Considered
to Meet Complex Health-Care Needs?**

Audience participation with panel of invited guests, including:

Joseph M. Kaufert, M.D., Ph.D.
University of Manitoba
Manitoba, Winnipeg, Canada
Russell L. Beeson
LIFECARE Services, Inc.
Pacheco, California

6:00p Dinner

Hosts, readers of Rehabilitation Gazette

Thursday October 15, 1981

8:00a Registration
Continental Breakfast

SESSION III

**THE PRESENT: TECHNOLOGICAL ISSUES - ARE PAST TECHNIQUES AND PRACTICES
DEVELOPED DURING THE POLIO CRISIS APPLICABLE TO MEET PRESENT NEEDS?**

The Evaluation of Technology in Response to Polio

John O'Connor, Moderator
Vice-President and General Counsel
National Foundation - March of Dimes
White Plains, New York

8:30a **Film**

Ernest W. Johnson, M.D.
Professor and Chairman, Department of Physical Medicine
Ohio State University Hospitals
Columbus, Ohio

9:00a **Health-Care Perspective**

Augusta Alba, M.D.
Director, Howard A. Rusk Respiratory Rehabilitation Center
Associate Director, Goldwater Memorial Hospital
Associate Professor of Neurology and Rehabilitation Medicine
New York University School of Medicine
New York, New York

- 9:20a **Reactor**
Ernest W. Johnson, M.D.
Professor and Chairman, Department of Physical Medicine
Ohio State University Hospitals
Columbus, Ohio
- 9:30a **Consumer Perspective**
Theodor A. Dukes
Research Scientist
Princeton University
Princeton, New Jersey
- 9:50a **Reactor**
Herbert S. Merrill
Engineer, State of Maine Rehabilitation Council
Falmouth, Maine
- 10:00a **Organizational Perspective**
Carlton Bishop
LIFECARE Services, Inc.
Augusta, Georgia
- 10:20a **Reactor**
Robert B. McCown, Ph.D.
Staff Scientist and Engineer
Intermagnetics General Corporation
Albany, New York
- 10:30a Coffee
- 11:15a **How Can We Apply "Space-Age Technology" to Meet
Health-Care Needs in a Climate of "Limited" Resources?**
Audience participation with panel of invited guests, including:
Eugene Murphy, Ph.D.
Veterans Administration
New York, New York
- 1:00p Lunch

SESSION IV

THE PRESENT: THE REGIONAL APPROACH TO MEETING NEEDS OF POLIO SURVIVORS OUTSIDE OF THE MEDICAL CENTER

What are the Institutional Alternatives that are Available on a Regional Basis?

Thomas R. Schworles, Moderator
Chairman, Education Committee
Illinois Congress of Organizations of the Physically Handicapped
Chicago, Illinois

2:15p **Health-Care Perspective**

Geoffrey T. Spencer, M.B., F.F.A.R.C.S.
Phipps Respiratory Unit, South Western Hospital
Consultant, St. Thomas's Hospital
London, England

3:00p **Reactor**

Augusta Alba, M.D.
Director, Howard A. Rusk Respiratory Rehabilitation Center
Associate Director, Goldwater Memorial Hospital
Associate Professor of Neurology and Rehabilitation Medicine
New York University School of Medicine
New York, New York

3:15p **Consumer Perspective**

Judy Heumann
Center for Independent Living, Inc.
Berkeley, California

3:35p **Reactor**

Valerie Brew Parrish
Associate Director, Career Planning and Placement Center
Southern Illinois University
Carbondale, Illinois

3:55p **Organizational Perspective**

André Dessertine
President, Association d'Entraide des Polios Handicapés (ADEP)
Paris, France

6:00p Dinner

8:00p Evening Discussion

-12:00p

Friday, October 16, 1981

8:00a Registration
 Continental Breakfast

SESSION V

PREMATURE AGING PROBLEMS OF POLIO SURVIVORS

Allen I. Goldberg, M.D., Moderator
Medical Director, Division of Respiratory Care,
Department of Anesthesia, Children's Memorial Hospital
Assistant Professor of Anesthesia and Pediatrics,
Northwestern University Medical School
Chicago, Illinois

9:30a **Define the Issue**

Frederick M. Maynard, M.D.
Assistant Professor, Physical Medicine and Rehabilitation
University of Michigan
Ann Arbor, Michigan

10:00a **Analyze the Issue**

Ann A. Bailey, M.D.
Staff Physician
Roosevelt-Warm Springs Institute for Rehabilitation
Warm Springs, Georgia

10:30a Questions from Audience

10:45a Break

10:50a **Solve the Issue**

Augusta Alba, M.D.

Director, Howard A. Rusk Respiratory Rehabilitation Center
Associate Director, Goldwater Memorial Hospital
Associate Professor of Neurology and Rehabilitation Medicine
New York University School of Medicine
New York, New York

Harriet Bell

President, Polio Survivors Association
Goldwater Memorial Hospital
New York, New York

Mary Jay Bullock, O.T.R.

Rehabilitation Medical Department
Johns Hopkins Hospital
Baltimore, Maryland

D. Armin Fischer, M.D.

Chief, Chest Medicine Service
Rancho Los Amigos Hospital
Downey, California

12:35p Lunch

SESSION VI

**THE FUTURE: CAN MODERN ORGANIZATIONAL APPROACHES TODAY
MEET THE CHALLENGE OF COMPLEX PROBLEMS OF TOMORROW?**

2:15p **What is the Future for the Polio Survivors?**

Henry B. Betts, M.D., Moderator
Vice-President and Medical Director
Rehabilitation Institute of Chicago
Chicago, Illinois

Health-Care Perspective

Geoffrey T. Spencer, M.B., F.F.A.R.C.S.
Phipps Respiratory Unit, South Western Hospital
Consultant, St. Thomas's Hospital
London, England

Consumer Perspective

Linda Bienick
Communications Specialist
Continental Illinois National Bank
Member, Access Living Board of Directors
Chicago, Illinois

Organization Perspective

André Dessertine
President, Association d'Entraide des Polios Handicapés (ADEP)
Paris, France

Audience participation via directed comments to moderator
and invited participants by selected panel:

Health-Care Provider

Mathew Lee, M.D.
Director, Department of Rehabilitation
Goldwater Memorial Hospital
New York, New York

Consumer Perspective

Judy Heumann
Director, Center for Independent Living
Berkeley, California

3:30p Coffee

4:00p **Keynote Address**

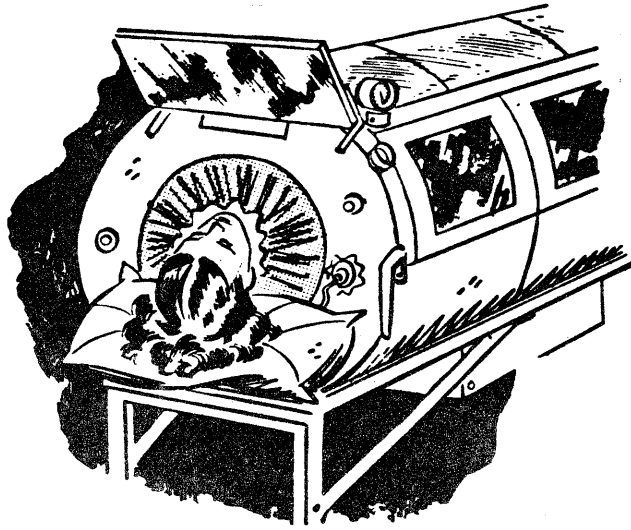
C. Everett Koop, M.D.
Deputy Assistant Secretary for Health
Department of Health and Human Services
Surgeon General Designee of the United States
Washington, D.C.

4:30p **Final General Discussion**

Henry B. Betts, M.D., Moderator
Vice-President and Medical Director
Rehabilitation Institute of Chicago
Chicago, Illinois

A monograph of the proceedings of this symposium will be available in the spring of 1982.
To reserve a copy (estimated cost of \$5.00), you may contact:

Don A. Olson, Ph.D.
Director of Education and Training
REHABILITATION INSTITUTE OF CHICAGO
345 E. Superior St.
Chicago, Illinois 60611
(312) 649-6179



POLIO HIGHLIGHTS

- 1789 Polio first described by Michael Underwood, a British physician, who asked other doctors "to pay attention to it."
- 1840 Dr. Jacob Heine, German bone specialist, learned that symptoms of polio result from damaged or destroyed nerve cells.
- 1890 Dr. O. Medin gave comprehensive description of symptoms and called polio an infectious disease.
- 1908 Drs. Karl Landersteiner and Erwin Popper in Austria showed that polio may be transmitted to the monkey, thus giving scientists an experimental animal in which to study the disease. They subsequently showed that polio is caused by a virus.
- 1927 Franklin D. Roosevelt, a polio victim, founded the Georgia Warm Springs Foundation, the first institution exclusively for polio.
- 1938 The National Foundation for Infantile Paralysis was incorporated "to lead, direct, and unify" the fight against polio.
- 1939 The first of 3,100 local chapters of The National Foundation formed in Coshocton, Ohio, on May 12. Dr. Charles Armstrong, of the U.S. Public Health Service, discovered that the Lansing strain of polio may be transmitted to cotton rats.

APPENDIX B

PROCESS DOCUMENTS

PROGRAM EDUCATIONAL OBJECTIVES (by session)

Session I

The Past: The Experiences of the Polio Patient

Objective of Session

Considering the international epidemic of polio in the fifties, the attendee will understand the nature of the health-care crisis and the process of the solution to meet the multiple needs it created.

Objective of Health-Care Perspective

Considering the morbidity and mortality of polio, the attendee will understand those technological advances (airway management, ventilator management) and those organizational advances (creation of a multidiscipline health-care team) required to improve clinical care.

Objective of Consumer Perspective

Considering the years of institutionalization required for care, the attendee will understand those psychosocial consequences of prolonged hospitalization and the effects upon individuals and their families.

Objective of Organizational Perspective

Considering the complexity of needs created by the scope of the polio epidemic in the fifties, the attendee will identify those organizations (government, insurance, associations, industry, institutions, etc.) that were involved with problem solving and will describe the processes employed to approach the challenge.

Session II

The Present: A Crisis? The Need to Develop Cost-Effective and Personal Services for Polio Survivors

Objective of Session

Considering current unmet needs of polio survivors and other individuals with similar respiratory problems, the attendee will identify and describe the present crisis of individuals who do not receive the medical and support services they require.

Objective of Health-Care Perspective

Considering available medical knowledge and resources, the attendee will understand the medical condition(s) that require(s) services that are currently inadequately available.

Objective of Consumer Perspective

Considering the current clinical and social situation of polio survivors and others with unmet respiratory care needs, the attendee will identify those elements of consumer concern that relate to and contribute to the crisis and its solution.

Objective of Organizational Perspective

Considering the capability of existing organizations involved with providing needed resources, the attendee will understand those barriers to the utilization of available resources in a coordinated and effective manner.

Session III

The Present: Technological Issues - Are Past Techniques and Practices Developed During the Polio Crisis Applicable to Meet Present Needs?

Objective of Session

After reviewing the existing and evolving technology that came to be because of the polio epidemic of the fifties, the attendee will determine if past techniques and practices can be employed to meet more modern needs of polio survivors and others with similar respiratory needs.

Objective of Health-Care Perspective

After describing past and present mechanical aids for breathing, the attendee will understand how present needs can be met by simple and inexpensive technology.

Objective of Consumer Perspective

After describing the subjective state of respiratory insufficiency, the attendee will be able to list the symptoms and the concerns of polio survivors that can be relieved by the appropriate application of technology.

Objective of Organizational Perspective

After reviewing the organizational resources and capabilities, the attendee will understand what technology is available, and can become available, and what process is required to utilize these resources.

Session IV

The Present: The Regional Approach to Meeting Needs of Polio Survivors Outside of the Medical Center

Objective of Session

After learning about other nations' programs which deliver health-care services outside of the institution, the attendee will identify the multiple approaches that can be taken on a regional basis to meet health-care needs outside of an institution in America.

Objective of Health-Care Perspective

After describing some regional approaches, the attendee will understand the facilitator role played by the health-care institutions in creating alternatives to prolonged institutionalization.

Objective of Consumer Perspective

After understanding consumers' experiences with alternatives, the attendee will appreciate the status of regional alternatives as they now exist in America.

Objective of Organizational Perspective

After analyzing organized approaches to alternatives to institutions, the attendee will understand those factors for success of related programs as they exist in Europe.

Session V

Premature Aging Problems of Polio Survivors

Objective of Session

After hearing the evidence given, the attendee will determine if there is a post-polio survival problem and will be able to describe it and identify the causes.

Objective of Health-Care Perspective

After hearing the scientific evidence, the attendee will identify the medical components of the problem.

Objective of Consumer Perspective

After hearing the consumer experience, the attendee will identify the psychosocial components.

Objective of Organizational Perspective

After hearing the organizational experience, the attendee will outline the organizational approach to the solution of the complex issues involved.

Session VI

The Future: Can Modern Organizational Approaches Today Meet the Challenge of Complex Problems of Tomorrow?

Objective of Session

Considering the complexity of involved issues, the attendee will understand the organizational barrier to approaching multidimensional health-care problems using the polio survival issue as an example. The attendee will identify the progressive steps required to meet modern health-care challenges.

Objective of Health-Care Perspective

Understanding the viewpoint of the health-care system, the attendee will better understand the future leadership role to be played by health-care institutions.

Objective of Consumer Perspective

Understanding the viewpoint of the consumer, the attendee will better understand the valuable contributing role of the consumer in the total picture.

Objective of Organizational Perspective

Understanding organizational structure and function, the attendee will understand limitation of existing organizational practice and identify new organizational approaches to face complex issues involving a multitude of forces and directions.

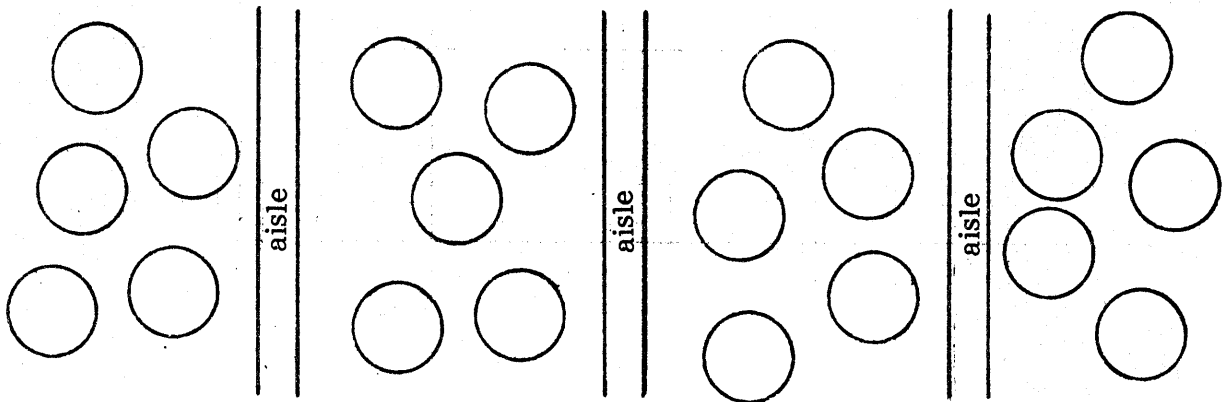
PROGRAM FACILITATION OBJECTIVES

During the working sessions on Wednesday (October 14) and Thursday (October 15), we will have small (less than 20 people) group discussions after each intermission. The geographic distribution of these groups will be spontaneously clustered around color-coded flip-charts:

Podium



Floor-level Table with Microphones for 7-10 People
(panelists, moderator, presenters, reactors, group reporters)



The group will have a recorder who will take notes and summarize the discussion for the proceedings. The group will have a facilitator who is either the moderator, a presenter, a reactor, a panelist, or a professional facilitator (volunteer).

After the discussion, a reporter, chosen by the group, will have three minutes to summarize the discussions with the panel.

The discussions will be focused on defined questions and issues, the objectives of the session. They will help the facilitator direct the discussion in such a way that the discussion leads to definite "action proposals" that will be meaningful for future health-care planning. The facilitator will be provided with a handout sheet for all participants to remind them of the objectives. The sheet will have the sessions, objectives, and the questions/issues to discuss.

Session I

The Past: The Experiences of the Polio Patient

Objective of Session

Considering the international epidemic of polio in the fifties, the attendee will understand the nature of the health-care crisis and the process of the solution to meet the multiple needs it created.

Enabling Objectives

Health-Care Perspective. Considering the morbidity and mortality of polio, the attendee will understand those technological advances (airway management, ventilator management) and those organization advances (creation of a multidiscipline health-care team) required to improve clinical care.

Consumer Perspective. Considering the years of institutionalization required for care, the attendee will understand those psychosocial consequences of prolonged hospitalization and the effects upon individuals and their families.

Organizational Perspective. Considering the complexity of needs created by the scope of the polio epidemics in the fifties, the attendee will identify those organizations (government, insurance, associations, industry, institutions, etc.) that were involved with problem-solving and will describe the processes employed to approach the challenge.

Discussion

What factors led to a successful approach to meeting the needs of polio patients?

The Question/Issue of Focus

Propose and rank three forgotten accomplishments that worked during the polio crisis that still can be useful today.

Session II

The Present: A Crisis? The Need to Develop Cost-Effective and Personal Services for Polio Survivors

Objective of Session

Considering current unmet needs of polio survivors and other individuals with similar respiratory problems, the attendee will identify and describe the present crisis of individuals who do not receive the medical and support services they require.

Enabling Objectives

Health-Care Perspective. Considering available medical knowledge and resources, the attendee will understand the medical condition(s) that require(s) services that are currently inadequately available.

Consumer Perspective. Considering the current clinical and social situation of polio survivors and others with unmet respiratory care needs, the attendee will identify those elements of consumer concern that relate to and contribute to the crisis and its solution.

Organizational Perspective. Considering the capability of existing organizations involved with providing needed resources, the attendee will understand those barriers to the utilization of available resources in a coordinated and effective manner.

Discussion

What factors today must be considered to meet complex health-care needs?

The Question/Issue of Focus

Propose and rank three actions that can be taken to mobilize existing resources to meet the needs of polio survivors and/or others with respiratory disabilities.

Session III

The Present: Technological Issues - Are Past Techniques and Practices Developed During the Polio Crisis Applicable to Meet Present Needs?

Objective of Session

After reviewing the existing and evolving technology that came to be because of the polio epidemic of the fifties, the attendee will determine if past techniques and practices can be employed to meet more modern needs of polio survivors and others with similar respiratory needs.

Enabling Objectives

Health-Care Perspective. After describing past and present mechanical aids for breathing, the attendee will understand how present needs can be met by a simple and inexpensive technology.

Consumer Perspective. After describing the subjective state of respiratory insufficiency, the attendee will be able to list these symptoms and the concerns of polio survivors that can be relieved by the appropriate application of technology.

Organizational Perspective. After reviewing the organizational resources and capabilities, the attendee will understand what technology is available, and can become available, and what process is required to utilize these resources.

Discussion

How can we apply "space-age technology" to meet health-care needs in a climate of "limited" resources?

The Question/Issue of Focus

Propose and rank three actions that can be taken to cost-effectively utilize technology to meet complex health care.

Session IV

The Present: The Regional Approach to Meeting Needs of Polio Survivors Outside of the Medical Center

Objective of Session

After learning about other nations' programs which deliver health-care services outside of the institution, the attendee will identify the multiple approaches that can be taken on a regional basis to meet health-care needs outside of an institution in America.

Enabling Objectives

Health-Care Perspective. After describing some regional approaches, the attendee will understand the facilitator role played by the health-care institutions in creating alternatives to prolonged institutionalization.

Consumer Perspective. After understanding consumers' experiences with alternatives, the attendee will appreciate the status of regional alternatives as they now exist in the United States.

Organizational Perspective. After analyzing organized approaches to alternatives to institutions, the attendee will understand those factors for success of related programs as they exist in Europe.

Discussion

What are the keys to success for a regional approach to health-care needs?

The Question/Issue of Focus

Propose and rank three actions that can be taken to better organize people to meet complex health care.

WHAT EVER HAPPENED TO THE POLIO PATIENT?

Advance Letter to 100 Medical Editors Explaining the Symposium

The polio era stimulated the development of technology, including the modern mechanical ventilator, which saved lives and permitted the survival of thousands of people worldwide who are now active contributors to society. This technology evolved into present-day life-support systems used in intensive care. The polio drama also led to the development of the goal-oriented rehabilitation process and the interdisciplinary team concept. These accomplishments now permit us to approach modern complex management problems created by newer epidemics (e.g., spinal cord injury from automobile trauma).

A present opportunity challenges us because of the greater development of technology and knowledge than of the organization of human resources to utilize them. For one example, individuals who require mechanical aids to support respiratory function now need medical and other services coordinated or developed to permit them to achieve the fullest potential of health and life. Other people, survivors of expert intensive care, inappropriately remain in expensive special-care areas which are costly economically and humanly, to the individuals, their families, and their care takers. And polio survivors face a present aging issue with uncertainty and fear.

We believe we can learn from history. We can study the development of ideas which responded to the polio epidemic. Solutions were found, worldwide, creating programs and services. The broad accomplishments on a regional basis were appropriate to the involved individuals, institutions, and communities. The most outstanding results were due to the limitless efforts of the polio survivors

themselves, working with their care givers and associations, who desired to control their own destinies.

We have been working during the International Year of Disabled Persons since New Year's Eve! All year we have been planning a celebration that would meet the goals of the United Nations' declaration and to create an international public awareness of the public health issues that challenge us. However, we do not want a fanfare, then to be forgotten! We want to create an effective model to approach complex health-care opportunities of today and tomorrow.

On October 14-16, 1981, an international group of selected individuals will meet in Chicago. We plan two days of a closed working experience to analyze past experiences in order to approach present issues. These individuals represent three fundamental groups: health-care providers, consumers, and related service organizations (government, law, insurance, associations, etc.). Many individuals -- polio survivors -- have multiple accomplishments and can address issues from several perspectives. All invited moderators, presenters, reactors, and guest participants are experts. The planned meeting design will stimulate the flow of ideas so as to make the meeting itself a process of working together -- the best approach to complex issues. The proceedings of the final day will be "open to the public." With a larger group, we will change our format as we analyze the current status of polio survival and attempt to approach future health-care planning. Our untraditional meeting will end with a keynote address to the issue: Can modern organizational approaches today meet the challenge of complex

problems of tomorrow?

We are grateful to our hosts, the Rehabilitation Gazette and the Rehabilitation Institute of Chicago; and to our sponsors, the National Foundation - March of Dimes; National Easter Seal Society; Children's Memorial Hospital, Division of Respiratory Care, Department

of Anesthesia; Northwestern University Department of Anesthesia; and LIFE-CARE Services, Inc. We additionally have multiple contributors who have aided the many people who will be joining us in October at their own expense. We will be all coming together, in celebration, to sow the seeds of multiple workings-together for the future.

Letter of Explanation

To: Invited moderators, speakers, participants, guests
From: Program Planning Committee - Allen I. Goldberg, M.D.
Re: Program Format

We are delighted you will come to our working symposium. You will be among a group of highly creative and accomplished individuals who are assembling together to solve complex issues. We shall successfully orchestrate a major demonstration of teamwork by following a predetermined plan. We have limited the size of our working sessions, but still they will feature many knowledgeable people. Our key to success will require following a process which encourages a rhythmic flow of ideas balancing each other in harmony.

Our group will assemble in one large wheelchair-accessible room. To encourage spontaneity and balance, we will communicate like a symphony orchestra. This theater-in-the-round will discourage audiovisual and other technological presentations and exhibits which can be arranged at informal sessions before or after the working symposium or during intermissions. If you wish to prepare a document to hand out, this can be done ahead of the session and can be photocopied one day in advance. However, please consider the effect of your document on the flow of communication when you prepare it. We need a rhythm which will result in a monograph that can benefit the many supporters of our meeting who cannot attend. We want a "score" for a re-performance!

Other documents provide the details of the meeting, the program, and the educational objectives and issues related for your needs. We have invited experts from every involved interest group in modern society that can relate to the topic of polio. This meeting will include health-care professionals, consumers,

manufacturers, insurance specialists, lawyers, government officials, organizational representatives, religious leaders, and others to guarantee that we consider the issues in the widest possible scope. Each major group (health-care providers, consumers, organizations) will have a perspective, and we have defined an educational objective for each major group at each session. We will study the past (one session), present (four sessions), and plan for the future (one session).

We have attempted to provide accommodations and a working environment to encourage an informal gathering. We hope all can meet the evening before to preregister and begin friendly introductions. Intermissions and evenings have also been planned to stimulate a relaxed social experience that will balance our working sessions. We understand the time considerations involved with daily living needs of some of our disabled guests, and we have done everything to plan with this foremost in mind.

Our working sessions will have the following process guidelines:

Moderators. You will conduct the process. Time for each individual contribution must be respectfully limited according to program requirements. Your goal is to facilitate the analysis of concerns and synthesis of issues to meet the three educational objectives of your session.

Speakers (including Reactors). You will prepare an individual "solo performance" to be balanced by a "solo response" from another expert. Your concise presentation will then catalyze a group response from other individual guests who are also

experts. Your presentation will set the stage for the direction of their creative energy.

Guests. Everyone is an invited guest participant. We are joined together to create a grand performance that we can all enjoy. We are celebrating the world's recognition of the issues

of disabled persons. We have focused on polio survival as only one example of issues facing us all today. We will demonstrate that all complex modern issues can be challenged as opportunities for our combined creative energies.

Letter of Explanation - Supplement #1

This supplement includes both general meeting objectives and specific educational objectives for each session. They are being provided in advance to stimulate your ideas and any preparation you wish to make for our working symposium.

As the meeting approaches, it becomes clearer that a significant document of proceedings will be generated. To help disseminate information, please try to prepare data, surveys, etc., as handouts which can be incorporated into the document and handed out in advance. We are not encouraging audiovisual presentations during the sessions which will detract from the rhythm. They can be arranged for interested groups around the scheduled proceedings.

We are likely having a group of 200 people during our working sessions (Wednesday, October 14, and Thursday, October 15). I am assembling a group of professional group facilitators who will volunteer to assist us in increasing the participation of all involved. I will be working closely with all moderators in implementing the proceedings.

Letter of Explanation - Supplement #2

You have all received (and/or can obtain at the Registration Desk) a blue letter of explanation and a supplement providing general meeting and specific session objectives. These objectives help concentrate attention to the public health focus of our working meeting. Although the objectives are defined, they give all participants flexibility in preparing their unique approach.

We want our symposium to do more than expose issues and identify problems. To best utilize the enormous creative energy of all participants, I request that each presenter and reactor list in writing, and possibly incorporate in his presentation, three proposed actions, in ranked order. These action-proposals will be compiled and edited to become a significant contribution to the proceedings. They will stimulate audience participation following session intermissions.

After each intermission, the audience will form groups of no greater than 20. These groups will have a short discussion led by one of the presenters/reactors, the moderator, or one of the several professional facilitators. This discussion will be recorded and incorporated into the proceedings. This discussion will then lead into a panel discussion to end the session.

EXHIBITS

Limited space will be available for exhibits of equipment and materials related to this program.

If you wish to provide an exhibit, please return this form with your name, address, and a description of the exhibit. Also provide us with details of your needs for the exhibit, i.e., space requirements, any extended outlets needed, etc.

Return to:
Elly Henig
Education and Training Center
REHABILITATION INSTITUTE OF CHICAGO
345 E. Superior St.
Chicago IL 60611

Exhibit Form

Name

Address

Phone where you can be reached daytime

Description of Exhibit

Special Needs

PERSONAL NEEDS

Type of respiratory aids used

Power needed (amps)

Time of day used

Total hours needed

Are you bringing an
assistant/attendant?

Name

Special comments

TRANSPORTATION NEEDS

Date & time of arrival

By air? Airport/flight #

By van?

Transportation needed from airport?

Height for parking space

Date & time of departure

By air? Airport/flight #

By van?

Transportation needed to airport?

REGISTRATION FORM

Name

Address

Phone where you can be reached daytime

Wednesday

Thursday

Friday

Days attending

Sponsored by

Affiliated group

Are you bringing an assistant/attendant?

Will you need assistance from the airport?

Upon receipt of your registration form, you will be sent information regarding hotel accommodations and transportation. We are hoping to reserve a block of rooms at special reduced rates including meals for symposium participants.

Please return registration form immediately in enclosed envelope to:

Elly Henig
Education and Training Center
REHABILITATION INSTITUTE OF CHICAGO
345 E. Superior St.
Chicago IL 60611

EQUIPMENT SERVICE AND RENTAL

Arrangements for equipment rental are the responsibility of the symposium participants.

Respiratory equipment may be obtained at LIFECARE Services, Inc., Batavia IL, (312) 879-1822, Tom Tierney.

Wheelchair equipment, batteries, and repair service are available at AAMED, Inc., (312) 771-2000.

REGISTRATION AND INFORMATION

Americana Congress Hotel - 2nd floor

| | | |
|------------|-------|----------------|
| October 13 | 7:00p | Francis I Room |
| October 14 | 8:00a | Francis I Room |
| October 15 | 8:00a | Francis I Room |
| October 16 | 8:00a | Francis I Room |

The Rehabilitation Gazette will be hosting a get-together on October 13 in the Belmont Room, adjacent to the registration. Please join them in meeting and welcoming fellow symposium participants.

TRANSPORTATION FACT SHEET

Ground Transportation from O'Hare Airport

Continental Air Transport, "South Loop" bus.

Leaves from all main terminals on the arrival (lower) level.

Schedule (7 days a week):

6:30a first departure

7:30a - 11:30p every 20 minutes

11:30p last departure

Fare: \$5.45 one way; \$10.10 round trip

Ground Transportation from Midway Airport

Continental Air Transport, "Downtown - South Loop" bus.

Leaves from the main terminal building at street level.

Schedule (Monday through Friday):

8:20a 3:00p

9:00a 4:10p

10:45a 6:35p

12:10p 7:15p

1:00p

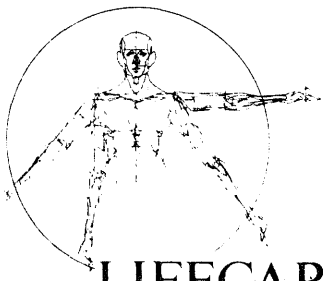
Fare: \$4.20 each way

If you have indicated a need for special transportation arrangements from the airport, you will be contacted individually regarding pick-up time and location.

HOTEL PARKING ACCOMMODATIONS

The Americana Congress Hotel has an arrangement with the Auditorium Garage for guest parking. It is located immediately west of (behind) the hotel, and guests can enter the garage from either Wabash Avenue or Congress Street.

The parking rate is \$6.75 per day, with a validated ticket from the hotel's bell captain. The Auditorium Garage's phone number is (312) 431-8707.



LIFECARE[®] SERVICES, INC.

2 W. Wilson St.
Batavia, IL 60510
(312) 879-1822

WELCOME

To help make your experience a most enjoyable one, arrangements have been made to assist you during this symposium, should the need arise.

For medical assistance, please call 880-4000 and ask for pager #518.

For respiratory-care assistance, please call 880-4000 and ask for pager #552.

For equipment assistance, please call LIFECARE Services, Inc., by dialing the hotel operator and asking for room #89.

Hopefully, these services will not be required by you, but we want you to rest assured they are available if needed. Thank you.

Instructions to Volunteer Staff

Dear Hosts and Hostesses,

At this time it is my pleasure to thank you for your interest and assistance with this symposium celebrating the International Year of Disabled Persons. Your participation has enabled this symposium to have the spirit for which it was intended, a spirit of cooperation and vision which exhibits the philosophy that no task is too great to be conquered, as long as we are willing to help each other and work together.

Your assignments as hosts and hostesses will be to add those personal touches which make any experience a pleasant one. One of our major objectives will be to help the symposium flow smoothly. I have attached maps and a time schedule for each day of the symposium. Please make yourselves available at the times and locations listed. Potential areas of major concern include movement from one session to the next, movement of disabled people, helping guests get set up for the next session, assisting with elevators, serving at coffee breaks, helping disabled guests to their cars or rooms, or any other problems which might arise.

A medical team of volunteers is available if any guests are in need of medical assistance. The medical volunteer coordinator is Ray Snarski, and the physician-on-call is Dr. Eveline Faure, room 701, pager #518. Transportation problems will be handled by Jim Boyd and Bruce Pendelton. We will also be able to call on the assistance of Elly Henig if there are any issues with the hotel which you cannot solve. The registration area in the Belmont Plaza area will be our central location to find additional assistance if needed. If no one is in need of assistance, please feel free to enjoy the symposium.

In an attempt to show our appreciation to all the people who have put so much effort and interest into the symposium, we would like to invite you to our "thank you" get-together. It will be Thursday evening, approximately 7:00 p.m., immediately following dinner in the Windsor Room. There you will be entertained by "Sunrise" and hear the debut of the song, "The Children's War," especially written for this symposium by Dill Taylor.

Hope to see you there.

Thank you again,

Karen Brandenburg

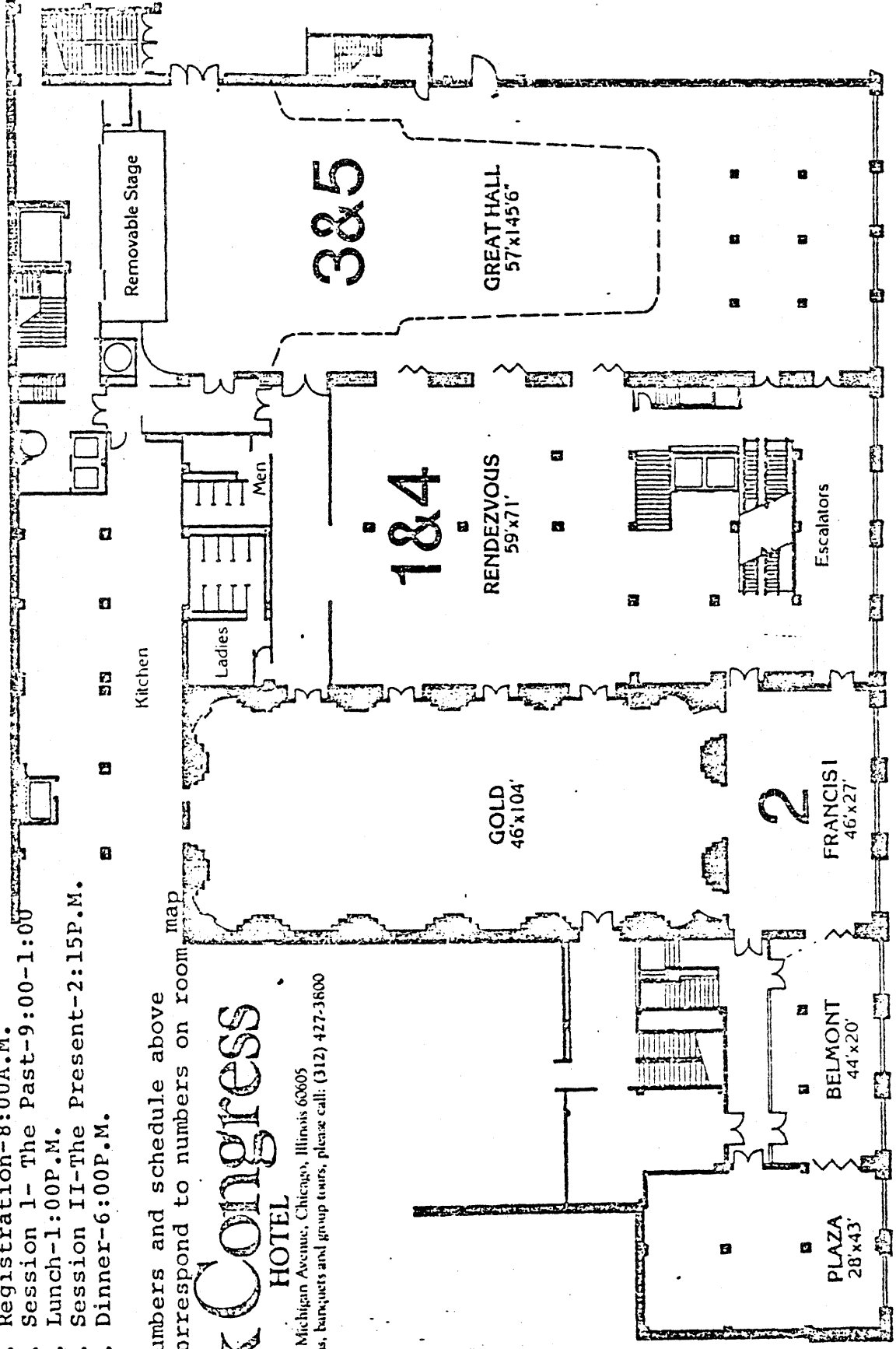
The Pick Congress blueprint for perfect meeting specifications

- Wednesday, Oct. 14th
1. Continental Breakfast-8:00A.M..
 2. Registration-8:00A.M.
 3. Session I- The Past-9:00-1:00
 4. Lunch-1:00P.M.
 5. Session II-The Present-2:15P.M.
 6. Dinner-6:00P.M.

Numbers and schedule above correspond to numbers on room map

Pick Congress HOTEL

520 South Michigan Avenue, Chicago, Illinois 60605
 settings, conventions, banquets and group tours, please call: (312) 427-3600



2nd FLOOR

MICHIGAN AVENUE

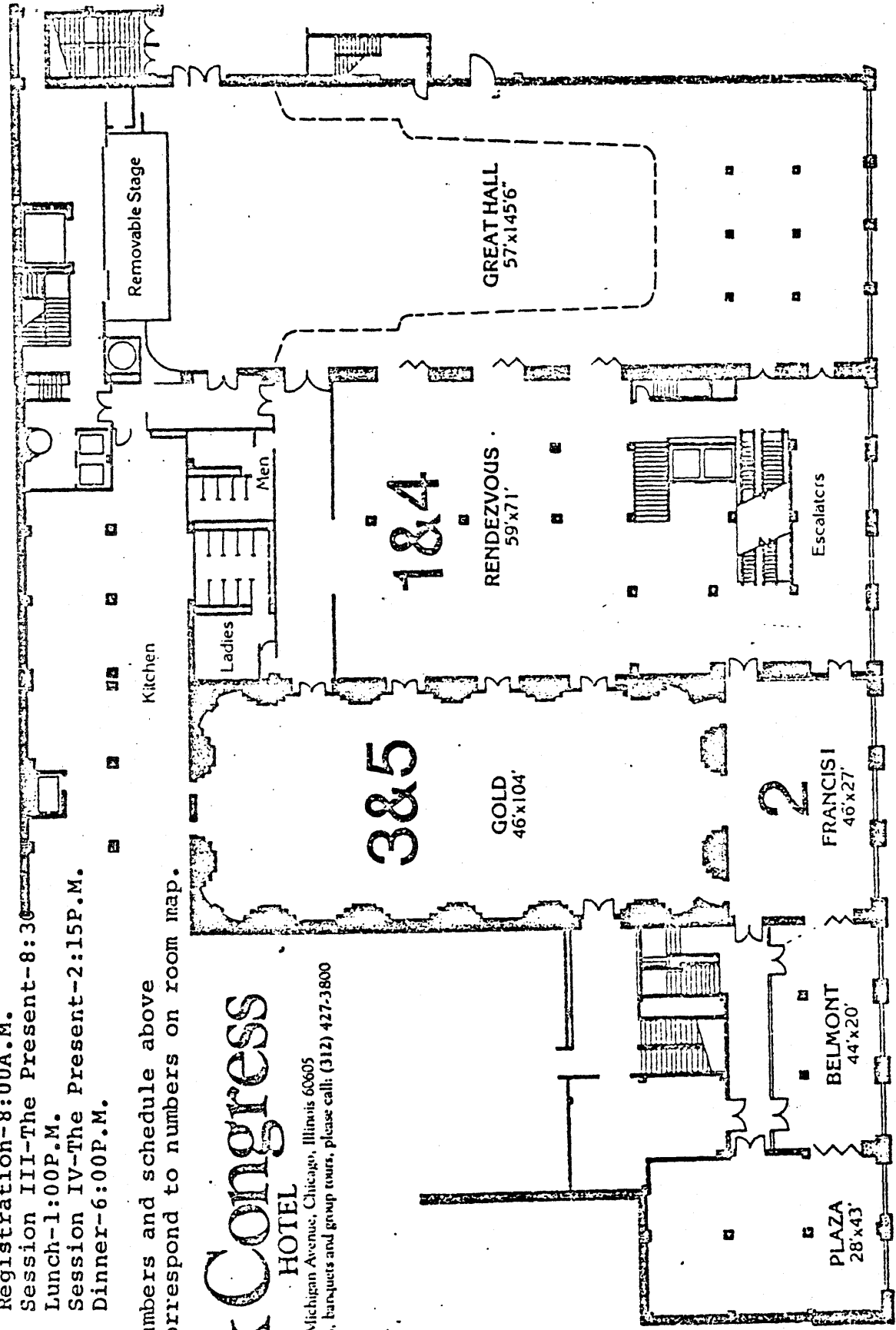
The Pick Congress blueprint for perfect meeting specifications

- Thursday, Oct. 15th
1. Continental Breakfast-8:00A.M.
 2. Registration-8:00A.M.
 3. Session III-The Present-8:30
 4. Lunch-1:00P.M.
 5. Session IV-The Present-2:15P.M.
 6. Dinner-6:00P.M.

Numbers and schedule above correspond to numbers on room map.

Pick Congress HOTEL

520 South Michigan Avenue, Chicago, Illinois 60605
 stings, conventions, banquets and group tours, please call: (312) 427-3800



The Pick Congress blueprint for perfect meeting specifications

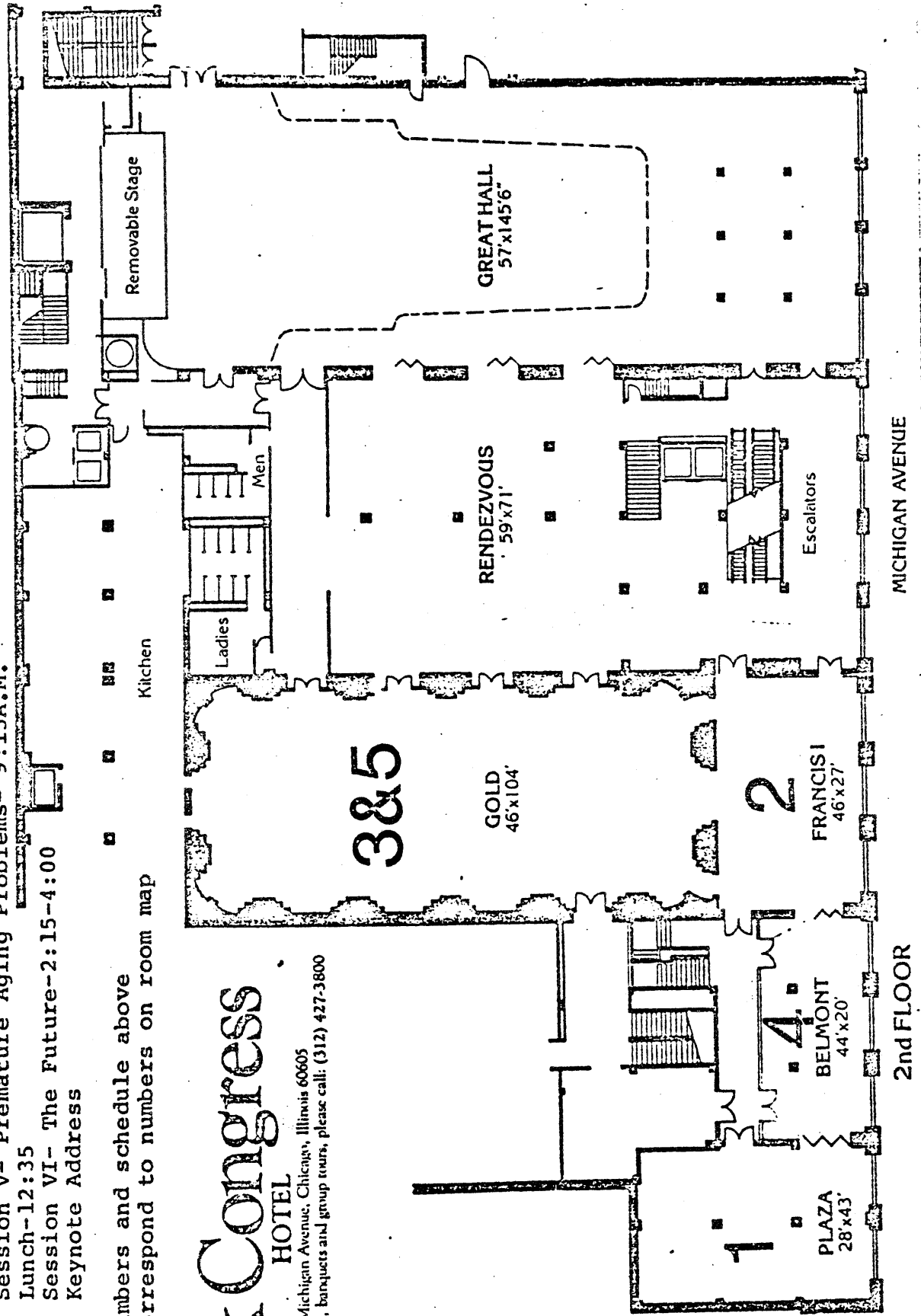
Friday, Oct. 16th

1. Continental Breakfast-8:00A.M.
2. Registration-8:00A.M.
3. Session V- Premature Aging Problems- 9:15A.M.
4. Lunch-12:35
5. Session VI- The Future-2:15-4:00
6. Keynote Address

Numbers and schedule above correspond to numbers on room map

Pick Congress HOTEL

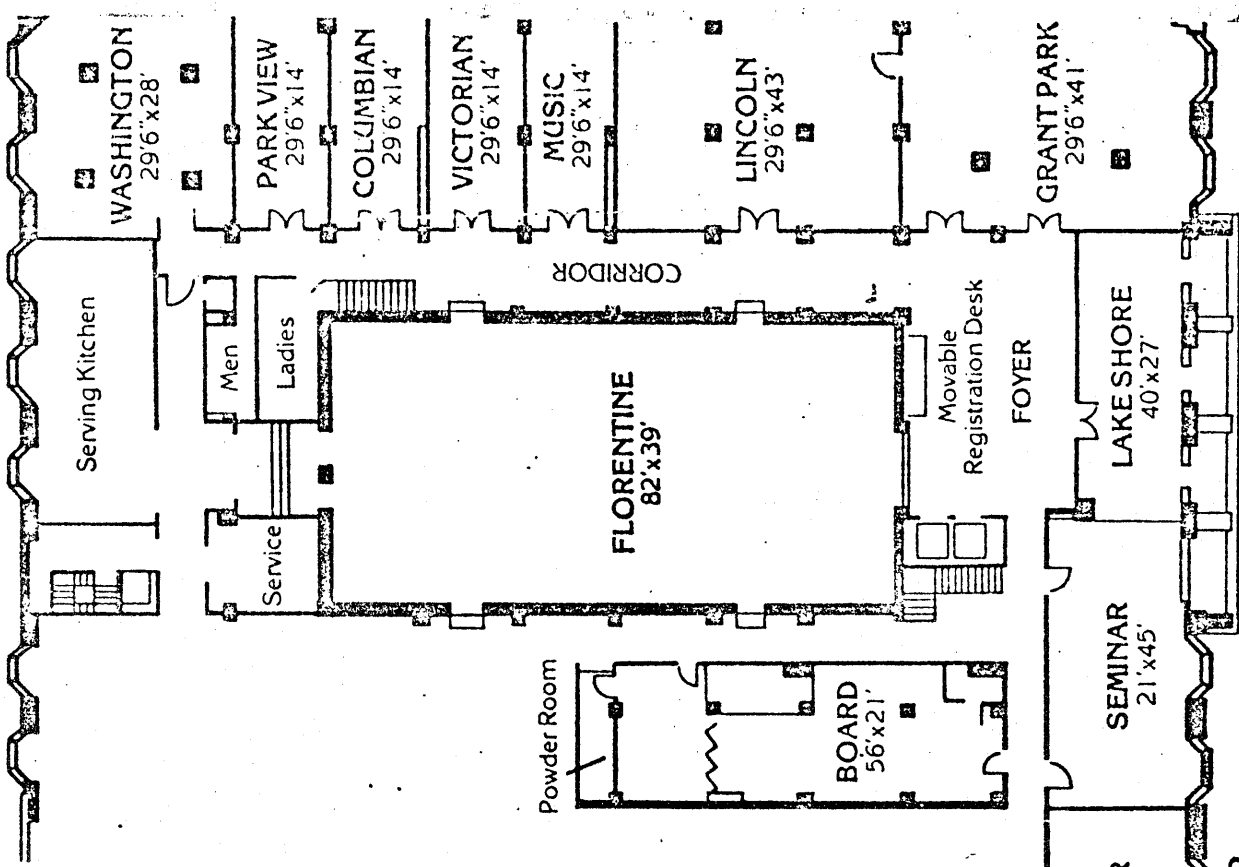
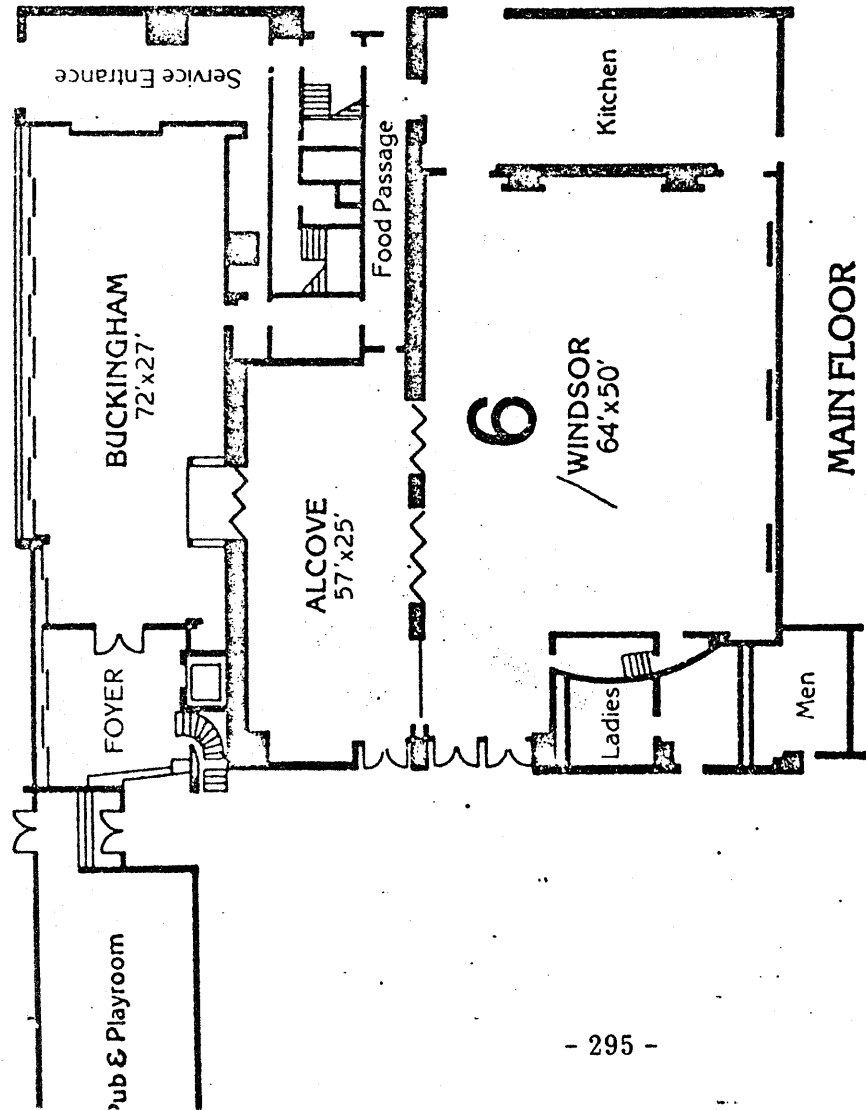
520 South Michigan Avenue, Chicago, Illinois 60605
 meetings, conventions, banquets and group tours, please call: (312) 427-3800



2nd FLOOR

MICHIGAN AVENUE

HARRISON STREET



MICHIGAN AVENUE

3rd FLOOR

APPENDIX C

**SUGGESTIONS FOR THE MEDIA
SYMPOSIUM EVALUATION
RELEASE**

SUGGESTIONS FOR LOCAL MEDIA STORIES

It is important to disseminate information to consumers and others on the issues surrounding people with disabilities and, specifically, post polio. We must take responsibility to spread word to our local news media regarding the concern of persons involved with polio and information derived from the symposium, "What Ever Happened to the Polio Patient?", which took place at the Americana Congress Hotel in Chicago, October 14-16, 1981.

Suggestions for a news/press release on this symposium were discussed:

1. Polio is a disease that still is in existence; therefore, education and research in the area are still necessary.
2. It has been estimated that many million children have not been vaccinated against the disease. Mandatory vaccination requirements are either not uniform throughout the United States or are simply not strictly enforced by the schools.
3. Polio occurrences are reported to the Center for Disease Control in Atlanta but are not publicized locally. Incidences are not of epidemic proportions in the United States, but there are scattered cases of polio.
4. A major concern should be the consciousness raising of both health-care providers and recipients.
5. An interesting and alarming point was raised concerning the potential for contracting polio. Certain areas, such as Central and South America where polio remains endemic, require no polio immunizations to travel there. Yet the World Health Organization has reported polio to be rampant in third-world countries.

This symposium was attended by people who had contracted polio during the largest epidemics of that disease in the United States. Many of these people who had polio are now experiencing unexplained symptoms such as muscle weakness, extreme fatigue, dizziness and headaches, shortness of breath, contractures, depression, and pain. The exact reason for these symptoms has yet to be specified, and they therefore remain a challenge to research in the area.

It has been noted that, for the most part, many physicians unaware and unfamiliar with the long-term effects of polio do not consider the possibility that these symptoms are polio-related. This can and does lead to inappropriate treatment. Research, information, education, and exposure of health-care providers to this information are necessary in order to devise some solutions for more appropriate care. It is important to stress that post-polio survivors require medical attention that is highly individualized, and they themselves most often are the most valuable resource with regard to factors concerning changes in their usual physical status. It is therefore imperative that active participation and collaboration exist between health-care providers and recipients.

This symposium has also brought to light the need for a stronger communication network between providers and consumers of health-care services, as well as among the consumers and among the professionals themselves.

All health professionals should have training and a central resource hotline for information regarding post-polio survivors.

Research into ventilatory and orthotic aids, and technological advances such as energy-saving devices and research into rehabilitation engineering should be fully utilized.

SYMPOSIUM EVALUATION

Content and Process

1. Were the definitions of the symposium appropriate?
 - . Goals of the symposium
 - . Objectives of the sessions
2. Was the process of the symposium effective?
 - . Presentation/reaction
 - . Small working groups
 - . Audience question/answer periods
 - . Major presentation
3. What did the symposium accomplish?
4. Was the cross-section of contributors/participants appropriate?
5. What positive observations did you make that should be incorporated into future endeavors?
6. Why do you think there was a successful interchange among professionals, consumers, and organizations?
7. What did you like best about the symposium?
8. What did you like least about the symposium?
9. Did the symposium meet your expectations?
10. Do you have recommendations for improvement of this symposium?
11. What steps now should be taken to continue the progress we have made in this symposium?
12. Other comments.

Transportation

Please identify your unique needs and services used: airlines, auto, Access Living, Bruce Pendleton at Rehabilitation Institute of Chicago, etc.

1. Was the transportation to Chicago adequate?
2. Was the transportation to and from the hotel adequate?
3. Was parking sufficient?
4. Did the coordination of transportation and personal service meet with your satisfaction?

5. What did you like best about the transportation?
6. What did you like least about the transportation?
7. Did the transportation meet your expectations?
8. Do you have any recommendations for improvement of the transportation?
9. Other comments.

Hotel Accommodations

Please identify your unique needs and services required: wheelchair, modified bathroom access, modified sleeping arrangements, etc.

1. Was the hotel room appropriately assigned?
 - . Area for equipment
2. Did the hotel room meet your physical needs?
3. Did the meeting rooms provide the appropriate settings for your work?
4. Were the meal services and hotel package of sufficient quality to permit us to try this approach again?
5. Were the attitudes of hotel staff conducive to the working spirit of the participants?
6. Was the accessibility of the hotel sufficient to meet your needs and expectations?
7. What did you like best about the hotel accommodations?
8. What did you like least about the hotel accommodations?
9. Do you have any recommendations for improvement of future hotel accommodations?
10. Other comments.

Respiratory Care and Other Services

Please identify your unique needs and services required: rocking bed, iron lung, electric wheelchairs, mechanical aids for breathing, etc.

1. Were the devices provided adequate for your needs?
2. Was the service provided courteous, reliable, and sufficient?
3. Were the charges for service appropriate?

4. What did you like best about the services provided?
5. What did you like least about the services provided?
6. Do you have any recommendations for improvement of services?
7. Did the services of organizations (LIFECARE, AAMED, etc.) meet your expectations?
8. Did the volunteer services meet your needs and expectations?
 - . Transportation
 - . Respiratory care
 - . Personal assistance
 - . Meeting facilitation
9. Other comments.

RELEASE

Date

I, _____, give my permission for the planning committee to use any material (written or oral) that I have contributed at the recent polio symposium. I understand that the committee will reserve the right to edit, add, delete, summarize, and otherwise alter the proceedings to transform them into a readable text. The proceedings will also include letters, interviews, chapters, articles, photos, and other information considered appropriate to the committee. All existing copyrights will be respected (author and publisher); written permission will be obtained. The final proceedings will be copyrighted by the Rehabilitation Institute of Chicago.

Signed

Exceptions noted

I, _____, give my permission for the insertion into the proceedings of any photographs taken at the recent polio symposium.

Signed

Exceptions noted



For additional copies contact:

**EDUCATION and TRAINING
REHABILITATION INSTITUTE OF CHICAGO
345 E. SUPERIOR STREET
CHICAGO, ILLINOIS 60611
(312) 649-6042**



A MEMBER of the McGAW MEDICAL CENTER of NORTHWESTERN UNIVERSITY