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**PROCEEDINGS OF  
REHABILITATION  
GAZETTE'S  
SECOND INTERNATIONAL  
POST-POLIO  
CONFERENCE  
AND SYMPOSIUM  
ON LIVING  
INDEPENDENTLY  
WITH SEVERE  
DISABILITY**

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**May 6 – 8, 1983  
St. Louis, Missouri**

**Edited By  
Gini Laurie  
Judith Raymond**

## ABSTRACT

Over 400 registrants, including polio survivors, physicians, and other health care professionals from around the world attended Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability held in St. Louis, May 6-8, 1983.

Conference topics included post-polio research, immunization, health maintenance, long-term ventilator use, ventilator equipment, and home care service programs for ventilator users and other severely disabled persons.

The symposium featured discussions of the independent living movement, both nationally and internationally, mechanical assistance with the new technology, family life, adoption, sexuality, fertility, and a forum for international exchange.

The goals of the conference were to 1) influence the development of home service programs and personal care attendants for ventilator-dependent and other disabled and elderly persons; 2) influence the development of a national and international network for all ventilator-dependent persons to coordinate services, treatment, funding, information, and equipment; 3) focus attention on the physiological and psychological effects of aging on the larger group of polio survivors; 4) disseminate medical information to the medical community on the changing needs of the polio survivors; 5) reactivate the general public's awareness of polio, hasten worldwide immunization, and alert travelers to checking immunization status; 6) enrich the independent living movement by demonstrating the relevance of independent living experiences of polio survivors to all disabled and elderly persons.

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PATRICK A. CLIFFORD  
PRESIDENT, C.E.O.

July 26, 1984

Ms. Gini Laurie  
Editor/Publisher  
Rehabilitation Gazette  
4502 Maryland  
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Re: "Proceedings of Rehabilitation Gazette's 2nd  
International Post-Polio Conference and Symposium  
on 'Living Independently with Severe Disability'."

Dear Ms. Laurie:

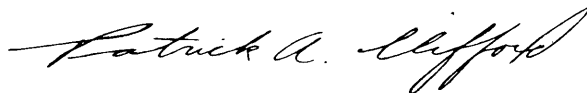
The C. V. Mosby Company is pleased to have been able to support the efforts of the Rehabilitation Gazette through our manuscript review and editing assistance with this publication.

The driving leadership and enthusiasm of Gini Laurie is contagious to all who come in contact with her. The mission of Rehabilitation Gazette to advocate for the independent living of disabled persons worldwide demands the support of all of us to provide information to as many as will listen.

Our best wishes for the continued success of the Rehabilitation Gazette and its leadership!

Sincerely,

THE C. V. MOSBY COMPANY



Patrick A. Clifford

PAC:10



A TRADITION OF PUBLISHING EXCELLENCE

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**Gazette International Networking Institute  
St. Louis**

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Gazette International Networking Institute  
4502 Maryland Avenue  
St. Louis, Missouri 63108

ISBN 0-931301-01-7 (pbk.)

Printed in the United States of America

Designed by Cynthia Hewett

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## AGENDA

Friday Afternoon and Evening, May 6

### Results of 1981 Polio Conference

4:00 pm Opening Session

6:00 Dinner

### Polio Immunization and Research

7:15 pm Worldwide Immunization

8:20 Research

### Polio Rap Session

9:15 pm to 11:15 pm

Saturday Morning, May 7

### Positive Attitudes and Health

#### Maintenance

9:30 am Positive Attitudes and  
Wellness

10:45 Health Maintenance —  
General

12:00 Lunch

Saturday Afternoon, May 7

### Long-Term Respirator Maintenance

1:15 pm Health Maintenance —  
Respirator-Users

2:15 Respirators/Ventilators

3:15 Home Care Programs for  
Respirator-Users

### Post-Polio Action Plans

Saturday Evening, May 7

### Celebration of Rehabilitation

#### Gazette's 25th Anniversary

6:30 pm Reception

7:30 Banquet

Sunday Morning, May 8

### Essentials of Living Independently

9:30 am Personal Assistants —  
Prevention of Burnout

10:30 Mechanical Assistance —  
High and Low Technology

### Rewards of Living Independently

11:30 Family Life. Natural or  
Adopted Children.  
Sexuality. Fertility.

12:30 Lunch

Sunday Afternoon, May 8

### Independent Living

1:30 pm The Independent Living  
Movement

3:00 Rap Session on Independent  
Living Centers

4:00 Adjournment

### Forum for International Interchange

4:15 to 6 pm

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\*Disabled

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*St. Louis Globe-Democrat photo by John Bloomquist*

These were among the more than 400 participants from 11 countries.

**PROCEEDINGS OF REHABILITATION GAZETTE'S  
SECOND INTERNATIONAL POST-POLIO CONFERENCE  
AND SYMPOSIUM ON LIVING INDEPENDENTLY  
WITH SEVERE DISABILITY**

**May 6–8, 1983, Sheraton-St. Louis Hotel  
St. Louis, Missouri**

**Edited by Gini Laurie and Judith Raymond**

# OPENING SESSION

## SUMMARY

Gini Laurie welcomed the participants as pioneers, as the representatives of all persons with severe disability "who wish to live on today's frontier of independence." The polio survivors of the 1950 epidemics were the pioneers whose self-directed lives at home demonstrated that home care cost one-tenth to one-fourth less than hospital care and who were the leaders of the independent living movement. The ventilator-dependent polio survivors, who have lived independently and productively for 25 to 30 years, are role models for all ventilator-dependent and all severely disabled persons.

The following six goals for the conference were presented:

- (1) influence the development of home care programs for ventilator-dependent persons and for personal care attendants for disabled and elderly persons;
- (2) influence the development of a national and international network for all ventilator-dependent

persons to coordinate services, treatment, funding, information, and equipment;

- (3) focus attention on the physiological and psychological effects of aging on the larger group of polio survivors, estimated at 300,000 who are not ventilator-dependent and relate the findings to all elderly persons;

- (4) disseminate medical information to the medical profession on the changing needs and changing technology of all polio survivors (specifically, arrange for the publication of the "Physician's Handbook on Polio," which the *Gazette* is correlating with Dr. Armin Fischer at Rancho Los Amigos Hospital);

- (5) reactivate the general public's awareness of polio, hasten worldwide immunization, and alert travelers to checking immunization status;

- (6) enrich the independent living movement by demonstrating the relevance of the long-time independent living experiences of polio survivors to all disabled and elderly persons.

## WELCOME

## GINI LAURIE

Welcome! Welcome to St. Louis and to the *Rehabilitation Gazette's* Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability. And, welcome to the celebration of the *Rehabilitation Gazette's* 25th birthday. Our welcome is symbolized by the omnipresent Chinese "Foo" sign, which means happiness, prosperity, and all good wishes to you.

Welcome to all you pioneers who have come from around the world — from Australia, Canada, England, Germany, India, Ireland, Japan, Mexico, El Salvador, South Africa, Sweden, and all over the United States, including Alaska. Many of you made personal sacrifices to pay your own expenses. Others used ingenuity to arrange funding by someone else. And all of you helped fund this conference by making donations to the Brown Bag Fund.

Perhaps you haven't thought of yourselves as pioneers . . . but you are! And it is appropriate that you are meeting here in St. Louis, within sight of the Mississippi River and in the shadow of the Arch, the symbols of the pioneers' gateway to the West. You are the pioneers of the 1950s, 60s, 70s and 80s. From this gathering of pioneers, we'll accomplish pioneering solutions to the particular problems of polio survivors and the related problems of all those with severe disability who wish to live independently.

Let's start by going back to the 1950s, to the six-

teen regional respiratory polio centers that were supported by the March of Dimes. They lasted for an average of about 6 years, until they were closed because the success of the vaccines cut donations to polio.

At the centers, you who were the medical directors were pioneers in coping with the unprecedented numbers of severely disabled persons who survived the polio epidemics. You pioneered a team approach that recognized the families and the patients as important members of the team. You demonstrated that the centers' team approach shortened hospital time from 1 year to 7 months. You pioneered a self-directed home care system for ventilator-dependent persons and proved that home care costs one-tenth to one-fourth less than hospital care. Most importantly, you pioneered a positive approach to severe disability.

You, the family members pioneered adapting your lives and your homes to the needs of your disabled spouse, parent, or child. Many of you here have been lovingly and responsibly on call for more than 30 years. You were patients (and there were almost 2000 of you survivors, who were ventilator-dependent), you left the hospital as patients and you adapted and adjusted and became self-directing individuals again in your homes, at school, at work. You were in charge of your attendants, your ventilators, your health mainte-

nance, your lives. You demonstrated the great difference between chronic illness and long-term healthy disability. In these overly cautious times, it is important to remember that those of you who are ventilator-users did *not* go home with nurses as attendants, but with *untrained* persons whom you could custom-train to suit yourself.

One of the principal aims of this conference is to show that, with support services, people with severe disabilities can be productive. People with severe disabilities can direct their own lives in their own homes. You who are ventilator-dependent and quadriplegic and are leading productive, self-directed lives in your communities are the living, pioneering examples. There is no need for statistics, no need to speculate if living independently is possible for ventilator-dependent quadriplegics. You *are* the proof — more than 25 years of proof.

Many of you completed your education *after* being disabled. You are now lawyers, professors, physicians, therapists, psychologists, salespersons, writers, homemakers, counselors. Many of you married and had children and raised families. You are parents and grandparents. No need to speculate if vocational rehabilitation and higher education are good investments for people with disabilities. You *are* proof — more than 25 years of proof.

You and your confreres around the world have lived quietly, making no big deal of living independently. With equally quiet pride, I have been publishing your articles on your experiences ever since I started the *Gazette* 25 years ago. But your experiences need to be more widely known because they relate to all others who are disabled or elderly and who require home services and personal care attendants. In fact, your experiences relate to *all* people. Any person may one day be disabled or elderly or require home services and personal care. And, in a larger sense, all persons should be actively involved with enlarging the potential for productive, independent lives.

In the 1970s, you began to realize this universal potential. You joined with persons who had all types of disabilities. Many of you here were among the pioneering leaders of the human rights movement for disabled persons. You were among the leaders of the organizations that formed the American Coalition of Citizens with Disabilities and organized the sit-ins that resulted in the implementation of Section 504 and other provisions of the Rehabilitation Act of 1973.

You who are participants from outside the United States demonstrate that the desire for independence and self-determination is felt by people with disabilities around the world. The evidence is in the independent lives that you are leading and in your presence here, despite many obstacles.

To sum up, you who are ventilator-dependent and who have lived independently for 25 or 30 years present a specific model to people with high-level spinal cord injuries and muscular dystrophy and a general model to all people who are severely disabled. You prove that people who are severely disabled can live safely and productively at home IF there are service systems and umbilical cord relationships to rehabilitation centers with respiratory expertise, IF disabled individuals and their families are instructed in the operation and maintenance of their ventilators, and, most importantly, IF there is a positive attitude toward the potential of each disabled person to choose and direct his or her own life.

Many of the physicians here are the pioneers who have been the most effective proponents of this positive attitude. What a powerhouse is here!

There are six goals toward which we can work and think together:

- (1) influence the development of home care programs for ventilator-dependent persons and for personal care attendants for severely disabled and elderly persons who require the assistance of another person to achieve the dignity and independence of living in their community and the opportunity to take control of their lives.
- (2) influence the development of a national and international network for all ventilator-dependent persons to coordinate services, treatment, funding, information, and equipment.
- (3) focus attention on the physiological and psychological effects of aging on the larger group of polio survivors — estimated at 300,000 — who are not ventilator-dependent and relate the findings to all elderly persons.
- (4) disseminate medical information to the medical profession on the changing needs and changing technology of all polio survivors. Specifically, arrange for publishing and worldwide dissemination of the handbook on polio being prepared by Dr. Fischer of Rancho Los Amigos Hospital, the Polio Survivors Association, and the *Gazette*.
- (5) reactivate the public's awareness of polio and hasten worldwide immunization against polio, emphasizing the importance of immunization of those who travel to areas in which polio is endemic.
- (6) enrich the independent living movement by demonstrating the relevance of the long-term independent living experiences of polio survivors to all disabled and elderly persons.

# RESULTS OF 1981 POLIO CONFERENCES

## SUMMARY

The *Gazette's* First International Post-Polio Conference in Chicago and the Post-Polio Symposium II in Oakland heightened awareness of the aging problems of polio survivors among the medical community and disabled individuals. Post-polio clinics were set up; additional conferences were held in 1982 and 1983; and an increased number of polio survivors sought information and checkups.

Developments for the long-term ventilator-dependent person were reported by Augusta Alba, MD: the number of vendors of ventilator equipment in New York City increased; regular respiratory therapy visits in the home were organized; a discharge planning manual was created; more hospital and community facilities became available; increased competition improved the portable volume ventilator; more scholarships for the training of personnel in technique of care were established; and the article in the *Gazette* on the use of mouth intermittent positive pressure ventilation for sleep triggered a deluge of letters and phone calls.

Allen I. Goldberg, MD was involved in the planning of the Surgeon General's Workshop on Children with Handicaps and Their Families, which was held in December 1982 at The Children's Hospital of Philadelphia. The conference was convened by Surgeon General C. Everett Koop, MD to consider ways of assisting the family to care for ventilator-dependent children at home.

Frederick M. Maynard, MD referred to the sessions on polio held at the American Academy of

Physical Medicine and Rehabilitation in Houston in November 1982 and the conferences held by nursing organizations in Michigan. He mentioned increased interest in ventilator-dependent spinal cord-injured persons at centers and hospitals and the change in Michigan in the willingness of third parties to pay for their home care.

Dr. Spencer discussed the disturbances of breathing during sleep caused by central apnea, obstructive apnea or progressive alveolar hypoventilation. He found Dr. Alba's methods excellent for preventing an excessive rise for people with abnormally high carbon dioxide levels during sleep. Otherwise, there is the danger that the high levels might not return to normal by day and the individual would have some daytime tiredness, headache, and even insomnia.

Drs. Yarnell and Berrol and Renah Shnaider, who organized the Oakland conference, felt there was a significant need for training post-polio survivors in basic health care and providing information on the resources of the community. Dr. Yarnell has set up a polio clinic and Ms. Shnaider is developing a support group to meet once a month to broaden the base of information and funnel this information back to the clinic.

Audrey King, MA, worked with the Ontario March of Dimes to organize a Post-Polio Workshop on April 22, 1983. At the workshop, a commitment was made to compile an Ontario registry of post-polio people and their family physicians.

### Developments for the Long-term Ventilator-dependent person

Augusta Alba

In the greater metropolitan area of New York City we've increased from one vendor for respirator equipment in the home to four vendors and a fifth one asking to join us. We've also established regular respiratory therapy visits in the home that started just about 2 years ago. Now it has increased so that these visits are as frequent as once a month, which means that the care that the ventilator-dependent quadriplegic receives is much improved. We've also had a greater amount of competition for the development of portable ventilators, so that we're seeing some very good models on the market, especially the new type that is being used in all types of respiratory disease today, the portable volume ventilator.

Another thing that has happened involves the dissemination of information. The Thompson Respirator Company itself has developed a newsletter

which it disseminates throughout the United States. As discussed later there is a polio information center one of my colleagues on Roosevelt Island in New York City has developed. One of the companies we are using came up with an excellent discharge planning protocol for the hospitalized respiratory patient.

Also I wrote an article on the use of mouth intermittent positive pressure ventilation for sleep. The need for this exists for children in intensive care units throughout the United States and especially in Chicago in the long-term care centers. Our center decided to expand, and at the present time we have eight children under the age of 7.

There has been a surprising development of facilities for the long-term ventilator-dependent patient both in hospital settings and in the community. We were able to place one of our ventilator-dependent quadriplegic patients in a Cheshire home in Tom's River, New Jersey. One of my former col-

leagues from Goldwater Hospital now is running a skilled nursing facility among many of his other duties. He has 30 paraplegics and quadriplegics, five of whom are ventilator-dependent. Montebello, which had been a long-term hospital in Maryland, became an acute rehabilitation center, and they've accepted eight ventilator-dependent patients. A young woman with spinal muscle atrophy, Connie Panzareno, is working with a respirator center and bought an old farm in Monticello, New York. She is now running a home for physically disabled adults. Her one dream is also to have ventilator-dependent children at this place. Bird S. Coler, our sister long-term hospital on Roosevelt Island, has opened 34 beds for ventilatory-dependent patients. Thus far, they haven't trained adequate nursing staff so they are only taking people who need oxygen, accounting for 16 of the 34 beds. Kingsbrook Jewish Medical Center in Brooklyn was not to be outdone, and their staff from the rehabilitation department have been to Goldwater and now are in the planning stage to open a similar unit in Brooklyn. These units open in both rehabilitation medicine departments and in medicine departments.

Fortunately, we have been able to have a scholarship fund for the training of personnel in the technique of caring for the ventilator-dependent patient. They usually come in during the summer, but we were fortunate this year to have a medical student from southern France who had worked with muscular dystrophy patients.

We've had a Japanese orthopedic rehabilitation specialist in for a week who cares for the spinal cord injured, and I was amazed to find they are handling this care almost as well in Japan as we are here. I think they have problems in actually placing the individual back into the home, but the in-hospital program is working.

We are gradually indoctrinating the thoracic surgeons in the use of artificial ventilators not only for patients with neuromuscular problems referred from general practitioners but also to substitute for the increased work of breathing in intrinsic lung disease. To date, most of the therapy has involved oxygen given during sleep or while the patient is ambulatory. But, actually if a bit more air were given, less oxygen may be needed. In the chronic obstructive pulmonary and intrinsic lung diseases such as tuberculosis, this is gradually coming into vogue.

Our work physiology laboratory has begun the testing and training of paraplegics and quadriplegics. Our staff in the physiology laboratory has been invited to speak at the American Association of Sports Medicine in Montreal.

Since 1955 we have supplied 24-hour home health aides if needed. The legislation passed in New York this April cut back the number of hours to 8 hours a day or less. We've enlisted a group of community legal service attorneys and all of our disabled in action societies and have already introduced a new bill to reverse this legislation.

### **The Surgeon General's Workshop on Children with Handicaps and Their Families**

Allen I. Goldberg

The Chicago conference in October of 1981 raised issues concerning the unmet needs of polio survivors and disabled people who depend on personal services and/or technology and who live in the community. We focused on the issues of organization of service, care delivery that was community-oriented and realistic, and, most importantly, reimbursement and funding issues that would make for mechanisms to permit the delivery of that care and those services. We put together information and shared it with all sectors: the private, including the Blue Cross Association and the Hospital Insurance Association of America, and the public, including the Waxman Committee, a Schweichert task force put forth by President Reagan to deal with the issue of Katie Beckett, and voluntary organizations and institutions on the East Coast and in the Mid West, including the Chicago Lung Association, the United Way, and the March of Dimes. As a result, individual case successes in meeting the needs of specific people, were possible and there is now more of an institutional awareness of these issues. Also, there were many individual calls for help, for information, for advocacy, and for case referral via the network we had created at our first meeting. Because of the network, people presented at that meeting who experienced respiratory failure called on Dr. Spencer in London and Dr. Alba in New York to inform their physicians of their unique needs. This literally saved their lives. Other people present at this meeting delivered healthy babies because of the network. Still others who read the proceedings came to us in Chicago and elsewhere and were referred to needed services through the network.

Funding issues were present, particularly affecting people who spoke at this meeting. Their funds were cut by the federal government because they were considered not disabled since they did so much. However, funds have been reinstated. Children in some states could not cross state lines because of red tape, but their funds were also provided. Furthermore, new resources were developed. Institutions, organizations, and hospitals who wanted to help people who had needs were now able to change and to redirect their missions with



their new capacities.

This all seems like a lot but still not enough was happening. We needed to reach a national consensus, to more widely disseminate the proceedings themselves and the issues raised. We went to Dr. Koop, the keynote speaker, who had said at the meeting, "It is my outstanding priority to work in such a way for the disabled of 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." We wanted him to make good on that promise. The result was the Surgeon General's Workshop on children with handicaps and their families held in December, 1982. The proceedings of this workshop already show changes in public policy at the national, regional, and state levels for children and soon will for adults as well. There will be continued efforts to disseminate information about the capabilities of severely disabled people in the community. In addition, at the World Congress of Emergency and Disaster Medicine in Rome, the emergency medicine community will learn of the benefit of helping people during the emergency and initial stabilization period. Also, a children's home health network has incorporated to deliver across-the-state services for disabled children. And we hope, to develop our own organization further as a national resource center to help those individuals and organizations who want to serve disabled people who depend on care and technology for life support.

#### **American Academy of Physical Medicine and Rehabilitation and Michigan Nursing Conferences**

Frederick M. Maynard

Since the conference was held, we have had a massive response in the form of letters and personal contacts by post-polio survivors describing the problems I discussed at the October meeting. These problems include the increasing weakness developing many years after polio. Those of us who had questions about whether this problem is real and how relevant it is among the 300,000 polio survivors have a much better idea of how widespread it is.

The problems I continue to see among those survivors who express concern about aging are really best described as degenerative problems of the muscles themselves, of the nerve supply, of the joints and soft tissues, of the ligaments and other structures that surround the joints and support the muscles' function. These problems are, of course, common in aging in general, but we see a great incidence among the post-polio survivors and see the increasing disability. Some responses to this situation are apparent in the new resources becoming

available. There are the clinics that Dr. Anne Bailey started in Warm Springs to specifically address this population need. There have also been local populations or clinics that have sprung up. It's really a delight to see some response to these problems.

I am seeing more interest on the whole subject of aging among polio survivors and the problems these people experience among the many fields in medicine. Dr. Goldberg referred to the sessions held at the American Academy of Physical Medicine Rehabilitation. There have been several nursing organizations in Michigan that have held conferences to deal with this subject. Neurology departments are again taking a new interest in it. There have also been several articles published in medical journals in the last 2 years on these subjects, so I think we are again providing some interest. I think the *Rehabilitation Gazette* has been one of the reasons for this renewed interest.

Another major area addresses one of the questions that came out of the conference in 1981 showing the similarities between the polio experience and the newer population group who are ventilator-dependent. In my own mind the problems that are being faced are clearly very similar. We've already heard reference to the funding problems. This includes funding for purchasing equipment, not only learning what is available; for arranging service and availability issues; and for obtaining insurance coverage. We've seen some change in the last year in Michigan about third party payers and their willingness to pay for home care plans for ventilator-dependent patients. I think there are more spinal injury centers and other hospitals around the country that are now creating special programs. We are finally launching a small one at University Hospital, and it is really very exciting.

The Center for Independent Living Movement continues, I think, to gain momentum. Again it was really started largely by the polio survivors. The spinal cord population are currently among the major recipients, but we are now seeing at Ann Arbor an inclusion by the Center for Independent Living of other disability groups, including the post-polio survivors.

This shows the third major area of change, which, I think, is really in society itself—increased awareness. One example of this is the Ford Motor Company in Michigan. Ford was the first American manufacturer to spend development and research money to design a vehicle specifically for the disabled population.

In the field of rehabilitation, planning efforts are underway for research programs to find out more about motor nerve problems in aging polio survivors. We need to get a better handle on ways we can approach treatment in the future.

## Reflections from England on the 1981 Chicago Conference

G.T. Spencer

I think I am incompetent to talk about the Chicago Conference because I live and work so far away and the most important results have been felt here. Nevertheless, as always, that won't stop me from putting in my sixpennyworth.

Although only two people came from England, Gill Whitworth and me, it has affected us in several ways, both good and bad. Firstly the good effects.

At that Conference I met Dr. Augusta Alba for the first time and learned about her techniques of mouthpiece nocturnal positive pressure assisted breathing. In June 1982 I paid a lightning visit to her hospital and I would like to take this opportunity of thanking her for giving up a whole day to showing me something of her work and for arranging for me to meet some of the people who use her method at home. I should like to thank them too because several had come to the hospital especially to see me.

Since that visit we have been trying out Dr. Alba's methods and I must admit haven't had quite the success she appears to achieve. This is most likely to be due to our own inexperience, but I would nevertheless like to describe our preliminary results.

Disturbances of breathing during sleep are a fashionable topic of much current medical interest. I believe we are seeing at least three different problems, which all too easily get confused.

(1) CENTRAL APNOEA. Certain patients with intrinsic lung disease (chronic bronchitis and emphysema) have disturbances in the regular rhythm of breathing during sleep. They show irregular changes in the depth and rate of breathing interspersed with short periods when no breathing occurs for 10-15 seconds. This is called central apnoea. It occurs predominantly in people whose arterial oxygen tension when awake is below normal and during periods of sleep apnoea oxygen tension can fall to alarmingly low levels. There is some evidence that central apnoea also occurs in people with polio and other neurological diseases.

(2) OBSTRUCTIVE APNOEA. This can be described simply as bad snoring. In normal people snoring is harmless at least to the snorer. In some people who are very fat or who have blocked nasal air passages, or weakness of the muscles of the mouth, throat and neck, it can cause serious reductions in breathing during sleep and periods of apparent complete obstruction when no effective breathing occurs.

(3) PROGRESSIVE ALVEOLAR HYPOVENTILATION. That is people who just don't breathe enough when asleep. I described this in some detail in Chicago, so I am not going to go over it again now, except to say that it appears to be almost en-

tirely confined to people with severe weakness or paralysis of the muscles of breathing or with gross skeletal deformity of the thoracic cage as occurs in scoliosis (spinal curvature) or after old fashioned mutilating operations on the thoracic cage, such as thoracoplasty. These conditions can conveniently be described as restrictive respiratory insufficiency.

Various combinations of these three types can occur in the same person and particularly following severe polio.

We have found that Dr. Alba's methods are excellent in preventing the first two types of sleep breathing disturbance, but find them less effective in preventing the third. Our preliminary results during night breathing studies on paralysed people using Dr. Alba's method suggest that they do develop abnormally high carbon dioxide levels during sleep, but the technique prevents this rise from getting severe or life-threatening. This contrasts with results using traditional methods of artificial ventilation during sleep with which it is often possible to maintain carbon dioxide levels within the normal sleeping range. Whether this difference matters or not we don't yet know. I suspect that it cannot be too serious or Dr. Alba would not have been so successful. Nevertheless, the danger is that if carbon dioxide levels rise excessively at night, the subject may not get back to normal by day, thereby suffering daytime tiredness, headache and somnolence.

Now, what to me has been a worrying result of the Chicago Conference. It focused a lot of attention on what has come to be called the "post-polio syndrome." There is no doubt that people with polio get weaker as they get older. So do we all. People who are already weak notice this earlier. Nor do I dispute the EMG evidence of late motor nerve changes which follow polio. Such studies must continue, but be evaluated critically and with full scientific objectivity. Unfortunately the current interest has prevented this from being done and some doctors dealing with those who have had polio are jumping to the conclusion that many troubles can be laid at the door of the post-polio syndrome without looking sufficiently closely for other more remediable causes of deterioration. An example may serve to illustrate my point.

A few months ago, a young man from California travelled all the way to England to see me. He had had polio as a child and though he could walk, he had flail arms. This combination is sometimes called, "upside down polio." He had had superb spinal surgery during adolescence to keep his back straight. Unfortunately this surgery had been preceded by a tracheostomy which had subsequently been closed. The spinal surgery had been pushed to the limit and had further weakened one of his legs. His complaint to me was that over the preced-

ing six months he had lost walking ability. He now found that after about fifty yards he couldn't take another step; if he tried to, he collapsed like a rag doll. He had consulted his physiatrist who arranged an EMG and told him he had post-polio syndrome and should take to a wheelchair. With flail arms this would probably have meant a mouth controlled powerdrive chair. He had also consulted his chest physician about worsening breathing. Following pulmonary function tests, he was told he had asthma and must take bronchodilators.

Brief questioning and clinical examination revealed that one leg had no quadriceps and he walked by locking this knee in full extension before putting weight on it. In recent months he had taken to sleeping with this knee bent. This had led to a few degrees loss of knee extension and it now took an extra effort from his weakened hip muscles to lock this knee on walking, which he could only maintain for a short distance. Within two weeks of starting to use a night splint to hold this knee fully extended, he was again walking two miles without difficulty. It was also interesting that tracheal x-ray revealed a narrowing of the previous tracheostomy site and it was this rather than asthma which was the cause of his breathing difficulty. Although this is probably treatable, it involves difficult surgery but at least he knows he hasn't got yet another disease.

I tell this story not to show off, although you may well think that I am, but to illustrate the dangers which can follow from the over-hasty attachment of the post polio syndrome label.

Finally, I want to deplore the various questionnaires asking for information about post-polio problems, which have started to be circulated since the Chicago Conference. These questionnaires provide uncontrolled data and can only lead to a false estimate of the severity of the post-polio problem. One of these questionnaires, from Warm Springs, Georgia, also offers medical advice. Some of which seems at least to be of questionable general applicability. Under "recommendations for former polio patients," Item 4 reads, "acceptance of reduced activity or bracing, if recommended by physician." I would urge you not to accept this advice and in particular the label of "Post-polio syndrome" until all possible treatable causes of increasing weakness have been properly excluded.

#### **Oakland Post-Polio Symposium**

Stanley K. Yarnell, Sheldon Berrol, Renah Shnaider YARNELL. There are several of us here involved with a post-polio symposium held in Oakland, California, in November 1981. Our conference had not nearly the scope or breadth of this one, particularly regarding political issues, and we intentionally geared it not so much at other professionals but at polio survivors. We wanted to answer some basic questions. We had a historical perspective offered

by a physician, Dr. Len Polocoff, who had studied physical medicine and rehabilitation primarily because of the problems he had dealt with back in the 1950s.

I discussed two issues at the program. One was the late deterioration phenomenon or post-polio syndrome. The other was aging with polio. In the subsequent year I looked back at twenty-eight patients I had seen for the first time just to see specifically what some of the problems were. These patients ranged in age from 30 to 84. For the most part the chief complaints were pain, fatigue, decreasing stamina and mobility problems. I broke some of these complaints down and came up with the following statistics:

1. Of the twenty-eight patients, seventeen had osteoporosis, or wear and tear arthritis of the joints. This can result from muscle imbalance.

2. Thirteen had problems in the shoulders, six in the knee, four in the hip, three in the ankle or foot, and two in the wrist.

3. At least two patients had fallen and suffered fractures, again related to osteoporosis.

4. Scoliosis was a frequent source of pain, whether it be caused by a disc problem, nerve root impingement, or stenosis. All twenty-eight patients had scoliosis to some degree, and seven had difficulty with sacroiliac joint pain resulting from the scoliotic curvature. Frequently there was some difficulty with the pelvic alignment, and the patient's weight was unevenly distributed.

5. Seventeen had problems with joint laxity, which is not unexpected.

6. Joint contracture also contributed to back pain.

7. Other problems that contributed to pain in people who had polio were carpal tunnel syndrome (5 patients), headaches caused by muscle tension (4 patients), fibrositis syndrome (3 patients), and thoracic outlet syndrome associated with curvature and rotation of the spine (1 patient). This last problem involves pain in the arm and is primarily vascular.

I looked at some other basic medical problems, and of those twenty-eight patients seventeen had late deterioration phenomenon or post-polio syndrome. I think it will be a point of discussion, but I believe it is important to rule out other sources of neurogenic problems, be they spinal problems, nerve root problems, or others. Ruling out other things is part of the definition. Nine patients had decreased pulmonary function. With regard to cardiovascular problems ten complained about purple feet, or cutaneous vascular insufficiency. Five had a problem with hypertension, five had difficulty with swelling in their feet. In terms of gastrointestinal or abdominal problems, eight of the twenty-eight had problems with hiatus hernia.

I want to emphasize that these are some of the significant problems with these aging post-polio survivors. This particular conference was not broad in scope, but it was geared toward post-polio survivors and some of the immediate needs they had.

**BERROL.** The conference in Oakland was predominantly patient-oriented. I think there are some very good reasons for this. The development of the disabled movement as a political force both in this country and in the world stemmed from that particular area of the country. It's also been mentioned by Dr. Maynard that many of the leaders of the disabled movement, particularly the independent living movement, came from the post-polio survivors. The post-polio survivors have had the longest experience in terms of being denied services and in terms of generalized knowledge on the part of both the medical profession and paramedical people as well. Society really wasn't prepared for the post-polio survivor. The post-polio survivor didn't know that. They weren't told that. It was only when the emphasis on spinal cord injury developed that post-polio survivors realized the significant strength in the numbers they had and readjusted their potentials. The spinal cord-injured patient wasn't led to believe that limitations were to be imposed on them the way the post-polio survivor was. The post-polio survivor came from an older age group and learned to adapt to society, to be acquiescent and not to fight, not to make waves. For example, the major role model of the post-polio survivor has been one who successfully hid his disability for a long period of time. When the spinal cord-injured people came into society, the post-polio survivors said, wait a minute, we should be part of that, too. As a matter of fact, we have some expertise that we've developed in terms of services. These survivors assumed the role of leadership and directed the disabled movement.

One of the problems has been that rehabilitation not only in this country but in the world has been based on vocational rehabilitation. A competitive or a sheltered vocational goal may in fact not be a reasonable goal. Only in the past 10 to 12 years have we come to realize that independent living is in fact a realistic goal. If the individual can attain a level of competitive employment, that is icing on the cake, rather than the end point itself. The post-polio survivors have been limited in terms of information exchange because they learned not to be aggressive, but rather to be passive; that was society's role for them. They accepted it and unfortunately lost a lot of time.

The one major attempt to provide the sharing of information has been the *Rehabilitation Gazette*. It has fulfilled this position over many, many years and formed the basis for the kinds of coalitions and

meetings that we are seeing now.

What kinds of demands are the post-polio patients placing on professionals in asking them to provide basic information? Dr. Yarnell talked about the emphasis being not only on the post-polio syndrome but also on aging, simple little questions of aging. What is the effect of aging on the post-polio survivor? What is the effect of polio on aging? The professionals have not addressed these questions because as we all know, polio is no longer a problem. That's what we've been told for 10 or 15 years. So nobody has really looked into it.

The emphasis of the Oakland conference was essentially to respond to the post-polio survivors in the community who said, "Look, we want information. We don't know or care what information you professionals share among yourselves in a scientific conference. We're going to be much more open-minded than you professionals will be, for we will have a conference that will share scientific information and we will invite professionals to attend. We have no problem in having professionals listen to what we have to present to each other." And so we did have a significant representation from the professional community, and I think the professional community derived an extra dimension that they didn't know they were going to get. They found that the post-polio survivor is an intelligent individual who is capable of understanding information and willing to go home and look up something they don't understand. This was not always generally accepted among professionals.

This concept of sharing information, important and intelligent information, where both patient and professional can learn together is a tremendously potent perspective that we were able to share. We provided a conference that was based on the model of a scientific conference, but all were invited to attend.

We weren't necessarily interested in, at that particular point, developing public awareness. The information exchange was the primary emphasis. But, needless to say, there was a significant input in terms of the media (TV, radio, and newspaper) that we were able to derive. This was a side benefit that we weren't necessarily looking for, but we felt it was desirable.

We also felt the significant need for training the post-polio survivor in terms of basic health care. The ordinary information one can get out of the *Reader's Digest* or medical journals is limited. Some of the information is good, but it doesn't necessarily apply to either the disabled individual or the post-polio survivor specifically.

One major emphasis was the development of a local network where information about community resources was available to the post-polio survivor. Given the average length of disability of the

post-polio survivor, it would be expected that he or she would have had significant information relative to community resources. But that's not necessarily so. Some way to share information was, we think, started.

SHNAIDER. At our Post-Polio Symposium in Oakland we had a panel of six post-polio individuals with varying degrees of disability. The advantage of having this panel was that they were able to talk about their gut-level feelings, fears, and anxieties. This responded to the widespread need to find someone who could help and understand. The areas of greatest concern included pain, diminished function, and methods of preserving function. Following the presentation there was a lengthy question-and-answer session and an eruption of dialogue involving all the people attending the symposium as well as the panel. The barriers were down, and this group was communicating on all levels. It was wonderful. The post-polio survivors and the professionals attending the symposium were enlightened regarding the unexplored areas of post-polio care some 30 years later.

In the Oakland-San Francisco Bay area we now know that there are many of us who share similar problems. We have a polio clinic established by Dr. Yarnell, and we know that individual treatment of physical problems can be designed to meet the needs of each person. We are currently planning a

post-polio support group to meet about once a month to broaden the base of information and to funnel this information back to the post-polio clinic.

I would like to state that I think we should continue to have post-polio events such as the one in Oakland. We in Oakland and in the Bay area hope that next year we will have our second symposium.

#### **Ontario Post-Polio Workshop**      Audrey King

Two of us from Ontario came to the 1981 Chicago conference and went away with the same enthusiasm and dream that many of the rest of you had. We went straight to the door of the March of Dimes and said, "Look, you guys began because of us. There's all these people in the States who are feeling all these concerns so there must also be people in Ontario, and we would like your support and your staff and your enthusiasm to help us organize our own conference." Two weeks ago, with the assistance of the March of Dimes and Lila Swanton from the March of Dimes, we finally got our little conference off the ground. There were 90 attendees from around the province, including a number of physicians. Already we have three pages of directives and time-phased plans from the March of Dimes in terms of the initiatives to be taken concerning networking, contacting conspiratory units, and looking at home care services.

# POLIO IMMUNIZATION AND RESEARCH

## SUMMARY

### WORLDWIDE IMMUNIZATION

Though vaccines have dramatically reduced the incidence of polio in the United States, the panelists — Father Lewis, a member of an order with missions in South America, Africa, and the East Indies; Mrs. Chaukar, a social worker in India; Dr. Spencer of London, who has treated polio throughout the Middle East as well as Europe; and Dr. Lusk, whose specialty is infectious diseases — warned that polio is still endemic in much of the Third World and that there are many psychosocial problems involved in worldwide immunization.

The magnitude of the disease is understated because of the underreporting of paralytic cases and the high proportion of unrecognized cases. Dr. Spencer quoted the estimate by Professor Huck-

step that there are 5 million new cases of polio in the world each year. The National Institute for Allergy and Infectious Diseases estimates 1 of every 200 children born into the world today will suffer paralytic polio.

Unimmunized adults planning to travel to areas in which polio is endemic were advised to be immunized with the Salk (killed) vaccine.

“Vaccine is available,” said Dr. Lusk, “and technology and know-how for delivery of the vaccine are available; what appears to be lacking is commitment of political leaders. Therefore, it seems to be reduced to a ‘people issue.’” He urged polio survivors to use their influence to eradicate the disease.

#### **Problems with Polio Vaccination** Patrick Lewis

I am a member of a missionary organization with mission fields in South America, Africa, and the East Indies. I receive letters from my colleagues in these countries, and one thing that struck me in a recent letter from Mali referred to the extent to which polio was still a concern of greatest magnitude in that country. I had assumed that since polio was more or less eliminated in the Western world by the vaccines, the same was probably true in the Third World. However, my colleague mentioned that in his own parish, 2,000 children recently had polio.

Polio is by no means eliminated in the Third World. The World Health Organization has set a goal for the elimination of polio by the end of this century, but from the statistics that I have read, it doesn't seem that they're going to make it. There are a number of problems about vaccination and about extending vaccination to the at-risk populations in these countries. It seems to me that one major problem is maintaining the “cold chain,” that is, the refrigeration of the vaccine so that it is preserved in the proper stage for vaccination. I believe Mrs. Chaukar is going to discuss problems with the sociocultural environment in which the vaccines are received, the way modern medicine is understood in these countries. Very often, particularly in African countries, people prefer injections to pills. There seems to be a magical conception of the power of an injection; a pill just doesn't have that. There is also the problem of training people at the right level to administer the vaccines. In some cases if the vaccines are not properly

delivered, they can, in fact, cause the polio rather than alleviate it.

#### **Polio Immunization — A Challenge in Developing Countries**

M.A. Chaukar

In big cities like Bombay where modern facilities are available, it was observed that many children were still not immunized. We therefore decided to study the difficulties involved in immunizing the children residing in urban areas. The analysis of the data was expected to clearly define the problems involved in the successful implementation of an immunization program against polio.

Our Institute and the area around it (about 1 kilometer radius) was selected for the present study. This included skyscrapers on one side, slums on the other, and a number of middle-class housing societies. The area under study thus was a fairly representative sample, including almost all socioeconomic groups.

One qualified nurse and four social workers were appointed to the project, and a detailed questionnaire was prepared to determine the magnitude of the problem. Every house was visited by volunteer social workers, and during interviewing the social workers educated the families whenever necessary and tried to convince them of the need to immunize their children. Pictures and posters were used as appropriate. The questionnaires were screened, and locality-wide lists of the children to be immunized were prepared.

The day of immunization was fixed for each area, and the local social worker circulated the information regarding day and time of immunization 4 days

in advance. On the day of immunization, a team of social workers accompanied by a trained nurse went where the children were to be immunized. The vaccine was carried in Thermos flasks with a sterilized syringe and spoons. The social worker went from house to house to call the children. When a child was not able to come for immunization the reason was noted. The nurse immunized each child after a preliminary checkup to eliminate cases of running nose, fever, and diarrhea. Each

child was then given a card for the record. This same procedure was followed during the administration of all three doses.

In the area under survey the total population was 40,000; 3,109 were children under the age of 5 years. Of these, 1,635, that is, 52%, were already immunized but the remaining 48% — nearly half — were effectively not immunized at the time of the survey.

Analysis of the data shows that 48% of the chil-

#### DEMOGRAPHIC DATA

Total families visited	6725
Population surveyed	40000
Children under age 5	3109
Children already immunized	1635
Partially immunized	281
Not immunized	1193

#### NUMBER OF CHILDREN WHO RECEIVED IMMUNIZATION DOSE

First	Number of children	Dropouts
First dose	1,321	—
Second dose	1,140	13.7%
Third dose	1,097	3.7%
Total dropouts: 17.4%		

#### SOCIOECONOMIC STATUS

Monthly income	Total number of children	Immunized	Not Immunized
Below Rs. 500 (\$50)	1,136	464 (40.8%)	672 (59.1%)
Rs. 500 to 1,000 (\$50 to \$100)	1,543	807 (51.6%)	736 (47.7%)
Rs. 1,000 to 3,000 (\$100 to \$300)	311	253 (81.3%)	58 (18.6%)
Above Rs. 3000 (\$300 and above)	119	111 (93.2%)	8 ( 6.7%)

#### LOCALITY ATTENDANCE FOR THE THREE DOSES

Sr. No.	Type of locality	First dose	Dropouts second dose	Second dose	Dropouts third dose	Third dose
1	Slums	1,020	140 (13.7%)	880	28 (3.2%)	852
2	Chawls	261	41 (15.7%)	220	15 (6.8%)	205
3	Buildings	40	nil	40	nil	40
Totals:		1,321	181	1,140	43	1,097

#### REASONS FOR DROPPING OUT

Reason	Number of children
1. Child not well at the time of the dose	77 (34.37%)
2. Out of station	78 (34.82%)
3. Gone out on the day of immunization	39 (17.41%)
4. Family migrated	22 ( 9.82%)
5. No responsible person in the house	8 ( 3.57%)
Total dropouts: 224	

#### NUMBER OF DISABLED PEOPLE FOUND IN THE POPULATION SURVEY

Nature of disability	Number of cases
Polio	45
Amputee	6
Blind	4
Epilepsy	2
Cerebral Palsy	4
Deaf	4
Others	12
Total: 77	

dren were not immunized at the time of the preliminary survey. The reasons cited for parents not immunizing their children were as follows:

- Did not know the seriousness of the disease 35.1%
- Children not well 25.4%
- Had gone out of station for long time 21.5%
- Lack of faith or superstition 18%

Though different reasons are given for not immunizing the children, the basic reason is lack of proper education and understanding of the seriousness of the disease.

People in the middle and higher income groups, who also have better educational status, have realized the importance of immunization. Thus only 15% of these children were not immunized.

The dropout rate between the first and third doses is 17.4%, which is significantly lower when compared with the statistics from other centers. The lowest dropout rate quoted until now was 40%. The reason for our low dropout rate was that our social workers took real pains to convince the public about the importance of immunization, to educate them, to try to remove wrong beliefs through discussions, and also to go from house to house to call them at the time of immunization. We also repeated all three doses within about a week's time to care for children who were not well or who had gone out at the time of immunization. An analysis of the reasons for our dropout cases shows that 34% of the children were not well at the time of immunization and the rest had gone out of station or had migrated. This means that with persistent efforts we can get nearly 70% results.

We may do the following:

- Gradual awareness of the need for polio immunization among the higher and middle classes has already started, but it has not reached the lower classes.
- More programs through mass media to educate the lower classes are necessary.
- A mass publicity campaign to educate the public and persistent efforts by government machinery with missionary zeal aided by voluntary agencies should make the immunization campaign successful.

### **World Immunization Against Polio**

G.T. Spencer

It has been estimated by Professor Huckstep that there may be around five million new cases of polio in the world every year. There is so far little to suggest that the number is declining. Indeed Huckstep suggests that with improved infant mortality rates in the Third World, epidemics of polio are actually increasing in size and number. His figure is based on combination and extrapolation from various

sources including the World Health Organization. Nobody can challenge this figure because in Third World countries where the disease is endemic, no records are kept and the great majority of new cases are not seen by doctors. Huckstep has been working with polio in Third World countries for many years and his figure is as good as anybody's and better than most. I want to quote an example of the uselessness of official figures. Some years ago I did a Consultancy for the World Health Organization in Baghdad, Iraq, where I saw people with untreated cholera, typhoid and polio dying unattended in the street gutters. When I asked about this I was told (1) it was the will of Allah that they should die thus; (2) the number of cases of these diseases notified to the international authorities each year was determined by the numbers notified from Israel. As the Arabs do everything better than the wicked warmongering Israelis, they always notified annual numbers, 10% or so below those notified from Israel.

In reality, Israel has one of the best services available for the prevention and treatment of these diseases. In most Arab countries such services are non-existent, so the true incidence there must be many times higher than official figures. Still, in the past 15 years I have treated 17 new cases of polio contracted by Europeans working in the Middle East and North Africa. I have seen thirty recent cases in well-to-do Arabs able to seek medical advice.

A particularly worrying feature of this is the number of people who visit Third World countries inadequately protected against polio. Many have sought medical advice on the required immunization prior to travel and been told that polio wasn't necessary. At present, in England, ordinary doctors giving such advice cannot be held in law to be negligent. This follows a High Court case a few years ago when a senior executive of the Shell Oil Company contracted polio very severely while on an assignment in Turkey. He subsequently sued the Shell Company doctor, whose advice he sought before going and in finding in his favour, the Judge said that while the Shell Company doctor should have been aware of health risks in all countries where Shell had employees, ordinary physicians could not be expected to know such things and that had he consulted a non-company doctor, he would not have won his case.

In addition to the Middle East and all Third World countries, polio is of course endemic in Africa which is of particular interest because chimpanzees and other higher apes also get polio and may act as a source of the virus. It is disgraceful that in no country in the world is immunization against polio compulsory for travellers. It seems remark-



able to me that at least those countries where polio is rare, have not introduced compulsory immunization for visitors. Compulsory smallpox vaccination for travellers has been common for more than a decade; though not only is smallpox a disease from which you either die or recover and are not left permanently maimed, but also the vaccine is more dangerous and less effective than either of those available to prevent the more damaging illness of polio.

This leads me to the regrettable fact that the levels of effective immunity among the population of so called polio-free countries are dangerously low. This is particularly so when one remembers that such populations have no natural immunity from childhood exposure.

The hospital where I work happens to be the hospital for the London Metropolitan Police. Young men accepted into the Police Force, and there is now a waiting list with many applicants rejected, are likely to be at least averagely responsible citizens and yet at a recent annual intake, only 20% were adequately immunized against polio. There is every reason to think that this figure is at least as good as that for the country as a whole. Nor do I necessarily accept the claim that in the deprived inner areas of American cities, over 50% of the population is effectively immunized against polio. Obviously I have no direct experience of these areas of America, but judging from published information about life in such areas, I cannot see how figures can be accurate. Recent anxieties about the safety of the vaccine for that comparatively trivial disease, whooping cough, have tended to further to decrease uptake of polio vaccine.

I have tried for the past 15 years to do something in my own country about what I regard as a national scandal. I have had no success. I have twice been on national television, talking about the need for sustained immunization against polio. One occasion followed some isolated cases of polio occurring in England and the other followed a serious epidemic in an isolated community in Holland who refused vaccination on religious grounds. I have arranged for three Members of Parliament to ask questions in the House of Commons about polio immunization and one Member of the House of Lords made a speech about it. All received complacent answers from Government spokesmen, saying, in effect, that polio is not a problem in England. I have confronted the British Association of Travel Agents with the fact that many of their members do not recommend polio immunization to those taking holidays in countries where polio is rife. Their answer was that mentioning polio might put customers off going. With a distinguished Professor of Virology, I wrote to the *British Medical Journal*, listing countries around the Mediterranean sea fre-

quently visited by holiday-makers, in which polio was common. The list includes Southern Spain, Southern Italy, Greece, Turkey, the Middle East and all North Africa. The only response was a letter from the National Tourist Office of one of the listed countries, saying in effect that we were trying to knock their tourist industry to protect our own economy.

The international body which should be taking urgent action to eliminate polio, is the World Health Organization. It spends many times less on polio than it has spent in the past decade eliminating the last few cases of smallpox from the mountains of Ethiopia. Nevertheless in 1969 it became sufficiently concerned to set up a 10 year survey into possible dangers from polio vaccine, avoiding for 10 years the need to take any action. The results of this survey were published in late 1982 and led last month to a leading article in the *British Medical Journal*, saying in effect that polio vaccine was so safe, it was impossible to measure its dangers. It is no good for the World Health Organization to take refuge behind the real difficulties of getting effective polio vaccine to where it is needed. They did it for smallpox vaccine. It is true that polio vaccine deteriorates rapidly if not kept cold. Today this is a minor technical problem, relatively cheap to solve. All that's needed is the will to spend the money.

There can be no doubt that all polio vaccine is the safest and most effective vaccine that has ever been invented for use against any disease. Polio is the worst and most damaging disease affecting mankind today. It is becoming more common. For the richer countries not to put large sums of money into worldwide immunization programs is criminal complacency, for which we shall ourselves sooner or later pay the price of further epidemics in our own countries. This should be the most important message to come from this Conference, besides which our selfish blinkered concern with our own aging bodies or social conditions pales into total insignificance.

### **Efficacy of Polio Immunization**

Rodney H. Lusk

INTRODUCTION. Polio vaccines have been widely used in the United States since 1955. They have dramatically reduced the incidence of polio in this country, with the annual number of reported cases of paralytic disease declining from more than 18,000 in 1954 to an average of less than 13 from 1973 to 1980. I would like to discuss the types of poliovirus vaccines available, the rationale for choice of vaccine, and the recommendations for use of vaccine for both infants and adults. Most of my information comes from the recommendations of the United States Public Health Department and

therefore reflects factors that may be unique to the United States.

**EPIDEMIOLOGY.** Poliovirus is present worldwide, and the infection is spread almost entirely by human contact. Inapparent infections are the largest reservoir for transmission by far; the ratio of inapparent infection to disease ranges from 50:1 to 500:1.

The disease remains a problem in much of the developing world. In 1980 41,836 cases were reported from 136 countries. These countries may be broken down to areas of Southeast Asia (40% of all cases), the western Pacific (22%), the eastern Mediterranean (20%), Africa (11%), and Central and South America (6%). Widespread underreporting of paralytic cases and the recognized high proportion of inapparent or nonspecific cases result in a clear understatement of the real magnitude of the disease.

**POLIOVIRUS VACCINES.** Two types of poliovirus vaccines are currently licensed in the United States: oral polio vaccine (OPV) and inactivated polio vaccine (IPV).

*Trivalent oral polio vaccine*, licensed in the United States in 1963, is a live, attenuated vaccine combining all three strains of poliovirus. Following full primary vaccination, long-lasting immunity to all three types occurs in more than 95% of the recipients. Most recipients are protected after a single dose. The vaccine consistently induces intestinal immunity that provides resistance to reinfection with polioviruses. It may also interfere with simultaneous infection by wild polioviruses, which makes it of special value in epidemic control campaigns. Use of the OPV has rarely been associated with paralytic disease in recipients or their close contacts (once in approximately 3.2 million doses distributed).

The *inactivated polio vaccine* was licensed in 1955 and has been used extensively throughout the world. It is administered by subcutaneous injections. Following primary vaccination with four doses, IPV produces immunity to all three poliovirus types in more than 95% of recipients.

**ROUTINE IMMUNIZATION (RATIONALE FOR CHOICE OF VACCINE).** It is recognized that both vaccines are effective in preventing polio. OPV has become the choice for primary immunization of children in the United States when overall considerations of risk and benefit for the entire population are taken into account. OPV is preferred because it induces intestinal immunity, is simpler to administer, is well-accepted by patients, results in immunization of some contacts of vaccinated persons, and has a record of having essentially eliminated disease associated with wild polioviruses in this country.

The debate concerning preference of type of

vaccine is not completely resolved. Some experts contend that the greater use of the IPV in the United States would provide continued control of naturally occurring poliovirus infection and reduce the problem of OPV-associated disease. They contend that there is no significant evidence of difference in the ability of the vaccines to protect individuals from the disease. The importance of higher levels of gastrointestinal immunity and the influence that transmission of vaccine virus to close contacts has on level of immunity in the community have been questioned.

**RECOMMENDATIONS FOR INFANTS, CHILDREN, AND ADOLESCENTS.** *Primary Immunization.* The primary series of OPV consists of three doses. In infancy this is usually integrated with the diphtheria-tetanus-pertussis (DTP) vaccination schedule. The IPV series consists of four doses. The schedule is also integrated with DTP vaccination. Supplementary immunization should be given to all children who received primary immunizations before they enter school. With the primary series of IPV, children should receive a booster dose every 5 years until the age of 18.

**RECOMMENDATIONS FOR ADULTS.** Routine primary immunization of adults residing in the United States is not necessary. Most adults are already immune and have small risk of exposure to polio in this country. However, immunization is recommended for certain adults who are at greater risk of exposure to wild viruses than the general population. These groups include the following:

- Travelers to areas or countries where polio is epidemic or endemic
- Members of communities or specific population groups with disease caused by wild polioviruses
- Laboratory workers handling specimens that may contain polioviruses
- Health-care workers in close contact with patients who may be excreting polioviruses

For unvaccinated adults in these risk groups, primary immunization with IPV is recommended whenever feasible. This is preferred because the risk of vaccine-associated paralysis following OPV is slightly higher in adults than children. Three doses should be given at intervals of 1 to 2 months and a fourth dose should follow 6 to 12 months after the third. Adults who have received less than a full primary course of either vaccine should be given the remaining required doses of either vaccine regardless of the interval since the last dose and type of vaccine previously received. Adults who are at increased risk of exposure to polio and who have previously completed a primary course of OPV may be given another OPV dose. Those previously completing a primary course of IPV may be given a dose of either vaccine.

As with all biological products, there are some precautions to be observed. It is considered wise on theoretical grounds to avoid vaccinating pregnant women. Also, patients with altered immune states or their household contacts should not receive OPV because of the theoretical risk of paralytic disease. IPV is recommended for these patient groups.

**CONCLUSIONS.** The prospects for the future of polio immunization programs were discussed at the recent International Symposium on Poliomyelitis Control organized by the Fogarty International Center, National Institutes of Health, at the Washington, D.C., headquarters of the Pan American Health Organization in March 1983. I did not attend but was able to read summaries of the conference. Most participants felt the disease could not be eradicated at present; some felt that even the year 2000 would be a difficult goal for achieving eradication of the disease. It was believed that the greatest obstacle to eradication was the lack of commitment by some countries whose leaders feel that the problem is not important enough for dedication of adequate health care resources. Data from the United States were encouraging, showing immunization rates of approximately 97% of all school-aged children and no new cases of wild polio disease reported in 1982. There was no consensus reached at the conference on the relative merits of the live oral vaccine compared to the inactivated vaccine.

It is certainly discouraging to see that a confer-

ence of experts feels that polio cannot be immediately eradicated and is unsure of an accurate timetable for a campaign to achieve that very desirable goal. I think in summary one can say that both vaccines are excellent for polio control; they are safe and effective vaccines, and the use of both should be continued, depending on local circumstances. Emphasis at the present time should be given to worldwide control with expanded vaccinations and tighter epidemiological considerations. I feel we are at the point where vaccine is available; technology and know-how for delivery of the vaccine are available; and what appears to be lacking is commitment of political leaders. Therefore it seems to be reduced to a "people issue."

Despite some of the pessimistic notes that I have mentioned, I am encouraged by the mere presence of all of you at this conference. You have assembled here the important tools to run the final campaign for eradication of the disease. Assembled here are representatives from many countries, developed and undeveloped. Assembled here are people who certainly understand the implications of the disease and what effects it has on one's life. No greater testimony and no more detailed collection of surveillance data are needed than this. I am greatly encouraged by your attendance at this conference and feel that one of the greatest resources we have is *YOU* with your enthusiasm and the impact and influence you convey to those around you in all of your homelands.

## RECENT POLIO RESEARCH

Joseph Kaufert, PhD, a rehabilitation epidemiologist at the University of Manitoba in Winnipeg, reported on his current follow-up survey of 1,500 nonrespirator and 186 respirator-dependent polio survivors, documenting the effects of aging and changing family support systems. There was much lower reporting of age-related changes within the nonrespirator group: about 20% reported significant changes in energy levels, and about 25% had significant arthritic and secondary limb effects.

"Some polio survivors experience not only residual weakness from the initial illness," says Dr. Dalakas of the National Institutes of Health, "but they also develop later in life a new progressive weakness. The mechanism of this new muscle weakness is unknown. Three basic possibilities have been raised, but none has been proved scientifically. One is the natural predisposition to de-

terioration that has been linked to the genetic background of the patient; the other is an acceleration of the aging process; and the third is reactivation of the polio. At the National Institutes of Health we have started to study post-polio patients to understand the mechanism of this new syndrome."

The panel and the audience concluded that "post-polio muscular atrophy" should be used rather than "post-polio syndrome." It is very, very slowly progressive. It is a degenerative problem common in the aging population in general. No one can predict who is going to develop the weakness and who won't. "There is no doubt," says Dr. Spencer, "that people with polio get weaker as they get older. So do we all. People who are already weak notice this earlier."

## Aging and Changing Family Support Systems

Joseph Kaufert

My own perspective as someone who had started to do a rather narrow comprehensive follow-up of a known group of respiratory polio survivors in one area of central Canada was greatly modified by the experience of the Chicago meeting.

We expanded the protocol that we had used to follow up the initial group to really deal with three of the main messages that came out of the Chicago meeting: the changes in rehabilitation technology over the lifetime of the survivors within our population of concern, changes in public policy and their implications for one known group of post-polio survivors, and, finally, the impact in a relatively isolated area of central Canada on changes within the self-help movement and the opportunities structure over the life of one group of survivors.

We were fortunate enough to have a comprehensive record of all essentially hospitalized polio patients within Manitoba, including about 1,800 of the total of over 3,500 cases. We also had an initial profile of their disability and we had an address list that was 30 years old. That was where we started 3 years ago. Our objectives were to look, using the original data, at the initial disability that people had, to look at the interaction of that disability with long-term aging prospects, and most recently to look at the impact of aging on the family, particularly the impact on spouses or aging parents, who were the primary sources of care. We tried to use a combination of medical records and an epidemiological follow-up to get an overall view of post-polio aging.

The label *post-polio syndrome* is as significant an issue for a researcher as it is for people who are working in rehabilitation medicine. That was one thing that we faced in the last 3 years with our follow-up study. We had to ask questions in such a way that people were not scared by it and would give reliable epidemiological information. Our own attempt to follow-up post-polio survivors in Manitoba succeeded in getting a fairly representative cross section. We were able to find or interview next of kin of 80% of the people with respiratory effects. The nonrespiratory affected were more difficult to follow-up.

We used vital statistics records, the provincial medical care information system, a search, in some cases, of marriage and death certificates. We were able to finally track down about 65% of all of the people who were validly identified as nonrespiratory polio survivors. This group interested me because I had been labeled as having nonparalytic polio. Our sample included about 25% of people who had confirmed lumbar function polio but no immediate acute respiratory effects.

A second approach that epidemiology can bring to understanding the post-polio experience involves studying particular epidemics, which is what we did in Manitoba. In 1952 and 1953 we had the highest level of case incidences, 300 per 100,000 individuals in Manitoba. There was strong impact on the local populations in these years. Also, we used these years as a baseline in having people recall their experiences and we could look at changes in rehabilitation services in Manitoba within a given time span. We looked at the development of services and of the independent living movement in central Canada within the spectrum of a single individual polio victim's life.

The first thing we found dealt with the reconstruction of the post-polio experience. We asked people to recall their experiences, and we compared the way they viewed their own early rehabilitation and acute effects with the data we had in the clinical record and in the medical record audit. We've done this for almost 800 people to date. We've found that about 45% of the sample had a direct adequate recall of what happened during the acute phase. Another 25% had partial recall, and the remainder were only young children at the time with the kind of polio that I had. They had a very dim recall of what happened during the acute stage. Just as they did for activities of daily living, they relied on significant others, on wives, or on parents to help them make sense of their acute, early rehabilitation experience.

We asked a series of questions having to do with how these people recall their early rehabilitation experience; and we were able to compare their views of the changes in their mobility and their activities of daily living with those of the patients with respiratory effects. We were able to match the memories of respiratory function level of nonrespiratory victims with some objective measures of respiratory status during that period of time. The significance was that although there were fewer reports of aging-related changes within the nonrespiratory group, a number of reports of respiratory effects within this group showed that these problems never received initial respiratory support. About 20% reported significant changes in energy levels. Another 15% attributed these to what they saw as post-polio aging.

The limb effects were much more significant; about 25% had significant arthritic and secondary limb effects. We were actually able to measure changes in mobility status at five points in time over the 30-year period. We found that nonrespiratory affected survivors initially had about 60% less body disability.

In 1982 we did a follow-up study, and about 46% continued to have major lower body impairment but only about 20% felt this imposed major func-

tional limitations. The statistics for upper body involvement were very much the same.

Finally I'd like to mention the isolation of the nonrespiratory post-polio survivors. In our respiratory cohort about 60% had major on-going contact with rehabilitation and respiratory medicine. About a third had major involvement in the independent living movement and had a political commitment to the things represented here. The nonrespiratory survivors showed a different orientation. Only about 15% had any care or any recent contact with specialists or medicine relevant to the polio experience, even though 30% of them had experienced medical episodes within the last year that caused concern about post-polio aging effects. Only 17% were even aware of the current concern for post-polio aging. Only 6% were tied into the major networks for independent living that would have provided them with information on the post-polio syndrome.

The hopeful side is that 34% were linked informally to networks with other post-polio survivors in what might be seen as an area of the tundra, where many concepts of independent living have not yet penetrated.

### **Post-Polio Muscular Atrophy**

Marinos C. Dalakas

What is the post-polio syndrome? Is it a weakness? Who should make the diagnosis? How was the diagnosis made? Polio is a neurological disease that affects the motor neurons. Post-polio weakness is also a neurological disease, and therefore neurologists have quite an experience in seeing this kind of patient and should make the differential diagnosis between this and other causes of muscle weakness.

Regarding muscular atrophy, it is known that some patients with acute paralytic polio experience not only residual weakness from the initial illness but they also develop later in life a new progressive weakness. The mechanism of this new muscle weakness is unknown. Three basic possibilities have been raised, but none has been proved scientifically. One is the natural predisposition to deterioration that has been linked to the genetic background of the patient; the other is an acceleration of the aging process; and the third is reactivation of the polio. At the National Institutes of Health we have started to study post-polio patients to understand the mechanism but also to be able to design some kind of effective therapy. Our study involves several comprehensive investigations, including the following: a complete neurological and neuromuscular evaluation by a competent neurologist who is an expert in neuromuscular diseases; a muscle biopsy of the affected muscles; electromyographic studies; vir-

ological studies of antibodies to poliovirus and other viruses (about 10 other viruses), both in spinal fluid and in the serum of the patients; analysis of the spinal fluid; and search in the serum of these patients for specific antibodies against nerve cells, the motorneurons. In addition we have analyzed the immune system of the patients, looking specifically at the lymphocytes, the white cells of the blood, because they are responsible for immune control. If post-polio muscular atrophy is caused by a persistent polio, the immune system may play a role because it is responsible for eliminating the virus.

For our study we have specifically selected the younger group of patients so we can avoid as much as possible the adverse effect that aging may have on the nervous system. All the patients had a history of partial recovery of function after the acute polio episode and minimum of 15 years of functional stabilization after recovery. We have studied twenty patients with new symptoms and were able to distribute these patients into two distinct groups. The first group, seven of the twenty, had deterioration of some functional capacity and stabilization without new muscle weakness. Their deterioration of function was often associated with local joint pains, frequent falling, decreased endurance, recurrent injuries, and instability. These patients had more joint pain than muscle pain. The contributing factors for this worsening of muscle function may be diminished reserve of strength, general reduction of physical fitness with aging, gaining extra weight, and the aging process itself. This deterioration of function appeared to occur in already weak muscles controlled by a depleted number of overworked motorneurons, which would have a limited ability to compensate for the further loss of motor units that occurs with advancing age. This therefore may represent deterioration with aging. These patients often remain in stable condition for relatively long periods of time when adjustments of their devices and braces are made or when work demands are reduced.

The second group, 10 patients, developed new muscle weakness in defined muscle groups. We call this *late progressive post-polio muscular atrophy*. These patients developed new weakness, wasting, muscle pains, and occasionally fasciculations in previously spared muscles, muscles that were unaffected even by acute polio or muscles that were affected and subsequently recovered. Because these symptoms progress slowly, these patients probably have a relatively benign but yet progressive disease.

Although the aging process might explain the symptoms that occur in already weak muscles or in muscles continuous with the weak ones, it cannot completely explain the weakness we have observed in muscles formerly not involved and re-

mote from the previously weak ones or weakness in young patients. This suggests to us that a new or an extended disease process may be taking place.

The question has been raised as to whether a polio virus can persist. There is evidence to indicate that polio virus can persist both in animals and in humans. *Whether the post-polio muscular atrophy I'm describing is caused by a persistent infection we do not know.*

In patients with new muscle weakness that we've studied further we noticed the following observations: (1) Through both electromyography and muscle biopsy active denervation in muscles that were not affected before. The muscle biopsy also showed inflammatory cells. These cells are lymphocytes, white cells, that are either around blood vessels or infiltrating the muscle fibers. This suggests that there may be immune cells sensitized against an antigen. (2) In spinal fluid from four of the seven patients we studied there were abnormal immunoglobulins, indicating to us the presence of an antibody against an unknown antigen. Analysis of the lymphocyte showed some changes in specific subsets, specific subpopulations of the

white cells responsible for the immune system.

We checked for antibodies to poliovirus in the spinal fluid and blood of these patients and noticed in the serum the antibodies to poliovirus were elevated in several patients. This is not significant because post-polio patients should have antibodies to poliovirus. It is important to see if these patients have antibodies to poliovirus in the spinal fluid. Of the seven patients studied only one had very high levels of antibodies to poliovirus in the spinal fluid. We don't know at the moment how significant this finding is. We are trying to confirm this finding with more special assays; if it is true, it is significant.

All these findings indicate to us that immune mechanisms may play a role in the manifestation of the symptoms in some of these patients. Whether this is caused by persistent polio we don't know. The study shows significant findings, but it is incomplete at the moment. We need to study more patients not only with new symptoms but also those without symptoms to serve as controls to see why some patients develop symptoms and other patients don't.

# POSITIVE ATTITUDES AND HEALTH MAINTENANCE

## SUMMARY

Jay Bullock, an occupational therapist at The Johns Hopkins Hospital, summed up her experiences: "A positive attitude to health is maintained by planning a program adapted to your needs and accepting the fact that some aspects of life will change as one ages."

"In terms of positive mental attitudes," said Dr. Maynard of the University of Michigan, "and how they affect wellness, the following are the most important: (1) belief and hope — belief that things can be better and hope for relief or improvement in the future; (2) control and self-direction — control over the way you experience disability and willingness to assume self-direction, which reflect self-esteem and self-confidence and are related to survival and success; (3) good health — something to be tended to by proper diet, exercise, and rest and by avoiding excessive drinking, smoking and similar social habits; (4) the ability to plan ahead and think for the future; (5) flexibility and adaptability — a willingness to reorder priorities; (6) humor — especially the ability to see humor in your own situation; and (7) being open for whatever comes along in life — not blaming people but rather forgiving people and yourself."

"My reflections relate to attitudes," said Mickie McGraw, art therapist at Highland View Hospital in Cleveland. "My own and those of the professionals around me. (1) Learn about compensating. It is a part of coping and the way one learns to live with

limitations. We have all done it before and we can do it again. (2) Do not automatically relegate all of our manifest symptoms to post-polio problems. Our nondisabled peers experience limits and losses of their own. We are special, but we are not alone. (3) Relate to yourself as a whole person. Do not focus on your disability. Set the example for your physician and your friends by your own attitudes and they will follow suit. (4) Balance — physical and psychic — is essential. It requires self-knowledge and self-control and preserves our ability to maintain control of our lives. (5) We should listen to our bodies' messages and acknowledge our physical vulnerability. Our spiritual invulnerability is our ability to adapt . . . and the ultimate key to freedom within limitation. We must keep faith with the collective will to survive, which is the call and spirit of this conference."

"Wellness is not a state," said Dr. Zola, a sociologist at Brandeis University, "that is an absence of disease. It is not a state. It is a process, a continuous process . . . The aspect of wellness must in some way be concerned beyond individual lifestyle, beyond individual behavior. It has to involve social and political spheres . . . For all of us, the nature of wellness or health must involve a certain kind of social support . . . One needs social support all the time, and part of a network of social support is a realistic perception of the environment out there."

## POSITIVE ATTITUDES AND WELLNESS

### Positive Health Maintenance Guidelines

Mary Jay Bullock

A positive attitude probably is stated by the old adage, "Lord help me to accept the things I cannot change, to have the courage to change the things I can, and the wisdom to know the difference."

There are today better guidelines being laid down for health maintenance in all age groups. We must ensure that these become properly adapted for people who have lived for years with the after-effects of polio. This conference is attempting to do this.

I think a positive attitude in relation to health maintenance is maintained by the following:

- Planning a maintenance program adapted to your needs.
- Accepting that some aspects of life will change.
- Not accepting that severe loss of function is inevitable.
- Assertively insisting that each medical problem or loss of function be carefully evaluated to determine the possible change aspects.
- Contributing your piece of knowledge to the pool that will help those with severe disabilities who follow you in this aging process.

**Positive Mental Attitudes** Frederick M. Maynard  
The first attitude is one of belief and hope. I think

that this attitude of looking at the future is extremely important. It's not so much just an attitude as almost a posture in life.

A second attitude is the knowledge that a person really is in control of his or her own experiences. Two different people can develop the same illness, whether it is a fractured leg or arm or a broken neck, paralysis, or polio, but how they experience that illness can be dramatically different. You as the individual are in control of the way you experience an illness. If you're going to be disabled, then you should fully experience being disabled, what it means to your life, and how it is different as compared to not being disabled. Then be done with the disabled experience so you can go on with what is important to you and not just with your disability, but with the other things in your life: your relationships, your jobs, producing something, contributing something.

Related to this knowledge of being in control of your own experiences is the self-direction of your health care. If severely disabled patients, including those dependent on ventilators have intact mental capacities and the right attitude, they are capable of directing their own health care, even if they can't assume the physical aspects of it themselves. *The person's willingness to assume responsibility for directing his or her health care reflects self-esteem and self-confidence.* Of course these attitudes have to be nurtured and developed before the person is able to direct his or her own life. Regarding this self-direction, the willingness and ability to direct personal health care may be, in fact, related to survival and success after disability.

A third mental attitude is one that holds good health as something that is precious and that must be tended. Is your health sufficient for what you want to accomplish, is it serving your purpose in life? If you maintain a caretaking attitude, you're going to become responsible for the things that you can't control in your behavior to influence good health, but again how you view your health and who controls it are the important issues. When you look at diet and exercise, controlling your weight, habits such as drinking or smoking that are not in your own health interests, you have to recognize who is in control, who is responsible, and whether it is interfering with your body's ability to function and serve you for your own purposes.

The fourth attitude is an ability to plan ahead and think for the future. People who are disabled are almost forced into more carefully planning out their lives than those of us who are able bodied. The planning necessary to get here was much more extensive for people in electric chairs and on ventilators than for those of us who walked on. Life is just more of a hassle, and you can either accept that hassle and enjoy going to the meetings, being with

people, doing a job, or enjoying yourself or not bother with the hassles and stay home, making your whole life revolve around taking care of your body.

The attitudes of flexibility and adaptability evidence a willingness to reorder priorities in view of changing resources. We hear about reordering priorities with changing resources from the government all the time. It occurs on a personal level as well. Your physiological resources or your body's ability to withstand stress, change as we are growing older, and we have to be willing to change our priorities with time.

A sixth attitude, for which I must credit Dr. Norman Cousins, is humor. Dr. Cousins describes the power that goes into a belly laugh, the kind of laugh when you're having a really good time. It produces an energy level and an excitement that very few other things can do; certainly no medications can give you that same real sense of energy. Dr. Cousins also pointed out the power of healing that comes with this energy. It is very helpful for disabled people to be able to see the humor in their situations, and there always is some humor if you are willing to let yourself find it.

The last attitude is being open for whatever comes along in life. Many things happen for which there are no reasons. A search for understanding, while it is important, especially for those of us in the medical field, can be an illusive journey. It just may be beyond our understanding. You have to be open.

Related to this is not blaming people or God for what has happened. The universe is rather random; that is the way life has been constructed. Some people have a hard time and some people have it easier, and you can fight and say it is unfair and pound and rage and be angry about it, or you can laugh and go on and ignore the fact that life just isn't fair.

Another aspect that relates to being open is the power in forgiveness. This means forgiveness of other people if they have contributed to what has happened or if they can't understand your position, and also forgiveness of yourself, both for what you may have contributed to your own problem or the way you are and what life has done to you.

### **Reflections for a Positive Attitude**

Mickie McGraw

Learn to live with your limitations. Learn about coping, about compensating. Our past experience with physical and other limits is a valuable resource if looked on as such. Through this experience we have proof that there are ways around and through whatever at the present may seem insurmountable. It is the inability to adapt to any given situation that often causes much pain and frustration.

View the post-polio problems as a natural aging



process made more difficult by limited reserve. It is important that we do not automatically relegate all of our manifest symptoms to post-polio problems. Our nondisabled peers experience limits and losses of their own. We are special, but we are not alone.

Urge your physicians to respond to you as a whole person and not focus on your disability. A simple but important addendum to this statement is relate to yourself as a whole person. Do not focus on your disability. Everyone else will follow suit. If I am comfortable in my disability, others will be too. I set the example by my own attitude.

Balance is essential. Do not push yourself. Learn what you can do and do not lose control. I still believe that physical and psychic balance is essential. It requires self-knowledge and self-control and helps to prevent pushing beyond what is healthy. Most important, it preserves our ability to maintain control of our lives.

It is no longer necessary for people who are disabled to prove they can do it better. Don't lose faith in your invulnerability. It is true that disabled people have had to prove something, many things, to themselves and to others, including not only that they can do it better but that they can do it best. As a result, a pattern evolved that often has prevented the disabled person from letting up. When another person would have given in to feelings of tiredness as being natural after a particularly busy day, the disabled person may push harder under the misconception that he or she shouldn't be so tired, that it is the extra burden of the disability, and that they must try harder. We should listen to our bodies' messages and acknowledge our physical vulnerability. Don't give up the struggle, but instead establish some priorities. While admitting our vulnerability we must keep faith with the collective will to survive, which is the call and spirit of this conference. It is our ability to adapt, to accept, and to change in response to the situation that is our invulnerability, the ultimate key to freedom within limitation.

### **Wellness and the Environment**

Irving Kenneth Zola

Wellness is not a state that is an absence of disease. I don't think wellness is a state at all, if by state we mean something that once achieved, is held forever. Whatever wellness is, to me it is a process, a continuous process.

A second aspect of wellness is that it is a creature of its environment, its social and political environment, and one reinforces the other. One of the dangers of modern medicine, at least on the social-physiological or ideological level, is that we tend to think of wellness as an individual state. We continually come down to what we as individuals can do. Wellness must in some way be concerned beyond

individual life-style, beyond individual behavior. It must involve social and political spheres. For all of us the nature of wellness or health must involve social support.

Perhaps the most neglected area of research involves positive attitudes and wellness. For the last 100 years a tremendous amount of research has focused on the psychosomatic area, specifically how we can think ourselves sick. What has been neglected is research on attitudes, on family structure, on trauma, on all sorts of things that may lead to a particular pathological state of breakdown. When this subject comes up, it seems to get, unfortunately, treated in the realm of anecdote and not in the area of systematic research.

One area where there has been research involves self-treatment, self-medication, and self-care. Self-care usually means the ability of individuals to follow the advice that medical regimens have set out. Self-treatment and self-medication refer to what individuals do to themselves on their own outside of the general purview of medicine. These areas have been neglected to the point that research is almost nonexistent. Yet people self-treat and self-medicate. All of you have probably within the last 36 hours taken some over-the-counter drug or substance or some other kind of food or drink that you are convinced helps you in maintaining your health or in preventing or alleviating symptoms.

We dismiss these actions as individual behaviors of little interest to anyone else. I submit that they are quite the contrary, that we must systematically collect data in these areas to find out if what we do is indeed worth doing, perhaps worth doing more than we do and worth reinforcing.

Ironically, besides not telling physicians what we do for ourselves, we also undermine the medical world by not doing what they prescribe. Let me give you an example: in the study of medical compliance, research usually concentrates on how the individual complies with a particular drug or regimen prescribed by the physician. Research is determined by the questions asked, so you only receive data that tells you an individual is or is not following that particular regimen under a certain set of conditions. If, however, you opt for more open-ended questions that cover essentially any condition an individual has, you find that people do many things in addition to whatever the medical world prescribes. You get a very different picture of what is going on in the individual's life, and you may see additional items that may be helping or hurting. You will see that, as in the chemical world, there are interaction effects in the psychophysiological world but most conceptual models haven't taken these into account. Both we and the research world have dismissed out of hand all those things we do for ourselves.

# GENERAL HEALTH MAINTENANCE

## SUMMARY

"The new post-polio syndrome is real," said Dr. Berrol of San Francisco General Hospital, "but there are many other causes for progressive weakness that occur to the post-polio person as a result of the aging process and as a result of some of the residual deformities that occur secondary to the disability rather than the onset of a new syndrome. The new syndrome is there but these other issues are far more common."

A dermatologist, Dr. Doneff, summarized basic skin concepts, emphasizing common sense and simple inexpensive management. "Oily skin is associated with polio and many other neurologic diseases . . . Two important things: flaking does not always mean dry skin; and virtually all 'complexion' problems are due to oiliness and blocking of the pores of the face and upper torso by old oil and cellular material . . . Your best friend here is frequent, gentle washing with soap and water."

Dr. Cameron of the University of Western Ontario called attention to the fact that we are perpetually reminded of various health hazards; one of these is smoking, another is obesity, and the third is salt intake. "People smoke for a variety of reasons," he says, "including peer pressure, the tranquilizing effects of the tobacco and, eventually, metabolic dependency. Breaking the addiction can be painful and depressing . . . Moderate obesity is as much a cosmetic problem as a health problem. If you like the way you appear, then you don't need to do anything about it . . . You should not add salt to your food, although you do not need to cut it out completely."

Linda Hennig, MA, RN of the Dallas Rehabilitation Institute, emphasized preventive health practices and health maintenance needs. Concentrating on the problems of women, she says, "Breast self-examination is considered to be the most effective way of detecting early breast cancer. In fact, 95% of all breast cancers are found by women themselves or their sexual partners and about 84% of breast cancers can be cured if they are detected early . . . For women who have experienced disability, the ability to perform self-breast examination may be significantly altered. . . . At our Institute, we developed a modified technique for those who could not perform the standard technique and taught a family member of other person they were totally unable to perform the technique."

Dr. Yarnell of San Francisco discussed exercise, emphasizing the need to suit exercise to individual differences. "General conditioning exercises or aerobic exercises," he says, "to maintain endurance and the overall tone of the cardiovascular system are good for post-polio people. The best is swimming, which exercises the muscles and stresses the heart appropriately. And, don't worry about the temperature of the water. . . . Another important form of exercise is stretching and range of motion, stretching not just your limbs, but your chest wall and abdominal musculature. . . . Don't overexercise your muscles. Know your level of fatigue. . . . Don't flog yourself using a manual chair; change to a motorized chair. Think of the change as a matter of conserving your energy and your joints."

### Neuromuscular Scoliosis and Polio

Sheldon Berrol

Neuromuscular scoliosis is perhaps the oldest spinal deformity known to man. Scoliosis that occurs as a result of polio is unique. Polio scoliosis is a rather specific form of scoliosis and involves a total C curve of the spine; patients with this represent only a small segment of the scoliotic patients we see. Scoliosis in children without neuromuscular disease is generally a localized type of scoliosis with a secondary compensation curve.

The person with scoliosis who has polio frequently will have a deviation of the pelvis as well, so in considering a surgical therapeutic approach, one must stabilize the pelvis before stabilizing the rest of the spine because the pelvis is what the rest of the spine rests on.

The polio scoliosis individual has residual flexi-

bility of the spine after reaching maturity. This means that this individual may continue to increase the level of scoliotic curvature well into adulthood. There are some measures we can take to prevent progression of the curve. Exercise, that is range of motion or flexibility exercise, helps by not allowing the muscles to become contracted in a curved position. The use of a lap tray or developing bilateral types of hand activity also helps. Bilateral-handed activities may in fact prevent some degree of progression of scoliotic curvature. Also, lateral trunk supports, which many of you have here, may be therapeutic if we exercise against the support.

One result of scoliosis is a limitation in the movement of the chest wall; as the spine collapses the ribs become more and more horizontal and less movable. The rib cage becomes deformed, rigid, and immobile — more immobile than the spine. As

a result of this immobility, there is a compression of lung tissue, limiting its mobility. The very small units of the lung, the alveoli, became about the same size as the residual amount of air left after a breath, so these air sacs don't fill properly. The lung tissue itself becomes immobile, which means filled with residual air, and this compresses the blood vessels of the lung, leading to decreased oxygenation. This is the problem that polio patients have. And it results in increased pulmonary artery pressure, creating pulmonary hypertension. Pulmonary hypertension is not the same as high blood pressure. As a matter of fact someone with pulmonary hypertension doesn't necessarily have to have high blood pressure and frequently doesn't.

### **Keeping It Together; Your Skin and Your Head**

Ronald H. Doneff

Oily skin and dry skin are common to almost all people at one time or another; they are simply managed if properly recognized. It has long been noted that oily skin is associated with many neurological diseases — polio, epilepsy, and Parkinson's disease, for example. The reason for the association has never been elucidated. Two important facts to grasp here are (1) flaking does not always mean dry skin and (2) virtually all "complexion" problems are caused by oiliness and blocking of the pores of the face and upper torso by old oil and cellular material.

Flaking problems occur especially between and in the brows, on the central or "butterfly" areas of the cheeks, and in the creases beside the nose and down toward the corners of the mouth — that is, the central face. The hairline, perhaps the skin behind and in the ears, and occasionally the midchest may also be affected, and many people who have this flaking will also have flaky scalps. This represents a condition called seborrhea or seborrheic dermatitis (dandruff is the mildest expression of this condition), and it is an oily condition. Resist what seems to be everyone's natural tendency, that is, to put creams or greases on the face or scalp. These can only make the condition worse. Your best friend, in fact, your best friend as a general rule throughout your life when talking about the face and scalp or "complexion" is frequent, gentle washing with soap and water. For seborrhea I advise the daily use of a dandruff shampoo such as Selsun Blue or Head & Shoulders; when the facial redness and scaling are stubborn, I even advise a daily, brief washing of the face using these shampoos as soap.

The second oily problem is what most people are referring to when they speak of "complexion problems" — the occurrence of blackheads, whiteheads, pimples or "zits," often in association with some of the yellowish red, flaky patches of

seborrheic dermatitis. This constellation of skin lesions comprises acne, and it's not so much a disease as a condition that affects most people to some degree from puberty or later.

Acne is a fairly complex problem involving oil production, closure of the pores, secondary bacterial accumulations and other factors, but for our purposes it is perhaps more important to understand what it does not involve. Acne does not involve dirt — even blackheads do not have any dirt in them; they turn black by oxidation, much the way iron turns red when it rusts. Acne does not involve sexual activity or practices. It does not involve allergies to anything. It does not involve vitamins or vitamin deficiencies. It does not involve "acid conditions" or "acid" foods. In fact, except in certain individuals, it probably doesn't involve the diet at all.

Very important is what people do to their skin, either leading to the precipitation of acne or in misguided attempts to treat it. Once again gentle soap-and-water washing two or three times a day (not more because it simply leads to a rebound overoiliness) is the foundation of simple treatment. Picking, squeezing, using grains, scrubbing with a washcloth or Buf-Puf all serve only to aggravate the problem, to convert little blockages into full blown "zits," and to produce or increase scarring. For faces that do not get too dry with plain soap and water, mild (2%–5%) preparations of benzoyl peroxide, available without prescription, are very helpful. It must be borne in mind that moderate dryness is essential but that overdryness or "burning" can occur from overzealous treatment. Simply decreasing the frequency of treatment, not stopping, is the answer. In no case should moisturizers be used.

Spontaneous dry skin of the face is a far less common problem than oiliness. It manifests as a light flaking of the peripheral portions of the face first and requires no treatment at all or only less frequent washing or the use of a nonsoap cleanser such as pHresh-3.5 or Purpose, and/or a simple moisturizing cream after washing.

Dry skin of the body, however, often coexisting with oily skin of the face, is an extremely common condition, especially in more northern climates. We have far fewer oil glands on areas of our bodies other than our face and scalp, and many of the things we do aggravate dryness. It will be worse in the winter because air, when it is brought in from outdoors and warmed, regardless of how it is warmed, expands and therefore holds less moisture than before it was warmed. In the warmer months today we mimic the winter situation by the presence of air conditioning. Additionally, we are, with the exception of certain overreactionary elements among us, an overly fastidious and over-

bathed society. Hot water (relaxing though it may be) and soap, too many times a day and in too many places, are the big culprits in producing and aggravating dry skin. Carried to the extreme, this causes flaking and itching — the old “winter itch” — and even fissuring, cracking, and various types of dry eczemas.

One very basic tenet must be learned here, and then managing the problem becomes utterly simple. The simple truth, although running against the stream of all the thinking we've done since childhood, is that dry skin does not need oil. It needs water! To illustrate: if you were to take a strip of skin from your hand or foot, or a piece of callus, and divide it into two portions and place one in a test tube containing oil and the other in an identical tube of plain water, and then observe the effects on the skin, you would be able to note that even after months of soaking in oil, the skin would never soften, whereas the piece in water would be virtually dissolved in a matter of hours! Think for a moment what happens to the skin of your fingers or toes when you've stayed in a tub too long.

The primary function, then, of the natural oils of our skin is to form a film to retard the evaporation of the moisture the skin contains. In bathing repeatedly with soaps, we continue to remove the oils and perpetuate a cycle of more and more evaporating and dryness. The simple solution, then, is to decrease bathing, to decrease the temperature of the bath water, to use soap only where it is needed, and then to use just hydrating soaps or applications of water, and to trap that water immediately with a moisturizing cream or oily cover.

The best, and most expensive, moisturizers are those containing lactic acid (2%–5%) and urea (2%–10%). (The stronger concentrations may cause some transient stinging or burning on some skins.) After the first few days, the soaks may be discontinued and just the moisturizers used. Creams are more helpful than lotions, and for overnight use, especially after soaking the hands or feet, greases such as Vaseline may be used.

In summary, flaking does not necessarily mean dryness; oily skin needs soap and water; and dry skin needs water and the prevention of its evaporation.

### **Smoking, Obesity, and Nutrition**

M.G.P. Cameron

In this society we are perpetually being reminded of various health hazards. One of these is smoking, another is obesity, and a third is salt intake. We know that smoking is injurious to health, as the Surgeon General says, in that it is significantly related to lung cancer and to emphysema, or chronic obstructive pulmonary disease. Smoking is also related to arteriosclerosis, particularly of the coro-

nary arteries, which nourish the heart muscle, and to high blood pressure. The major risk factors for two devastating diseases — myocardial infarction and stroke — include family history; abnormal fatty metabolism; abnormal carbohydrate metabolism, such as diabetes; high blood pressure; alcoholism; and smoking. Obesity in some ways shares many factors with smoking, particularly matters of peer pressure, life-style, and self-image.

A balanced diet will contain enough first-class protein to maintain the ingredients for replacement of body tissues. This amounts to 1 gram of first-class protein per kilogram of body weight, and that is considerably less than the amount of meat in a Big Mac. It can also be provided in the form of legumes plus seeds taken together. Legumes are beans, carrots, peas, and lentils; and seeds include sesame seeds, sunflower seeds, and peanuts.

Thirty-five percent or less of the diet should be in the form of fat, and the total number of calories will need to be less than that which you are expending. Fat, of course, besides being innate in a food, is part of the method of cooking; fried foods have a great deal of fat in them.

Vitamins and minerals in adequate quantities are available in a balanced diet as long as the total number of calories doesn't drop below about 1200. Additional vitamins and calcium will be necessary below that level.

The gastrointestinal tract does not work well in the absence of high fiber. The best high fiber is bran, but prunes, rhubarb, apricots, oranges, and figs are also natural laxatives. Fruits and vegetables should be eaten raw when possible and the skin should be included.

We require 0.5 grams of salt per day. Most of us actually eat between 8 and 10 grams of salt; that's twenty times as much salt as we need. If we retain sodium which is half of the salt molecule, we are more likely to retain fluid and therefore more likely to have hypertension or heart failure. These conditions should be avoided at all costs, so we should not add salt to our foods.

I would also like to comment on fluid intake.

Fluid intake will add tremendous calories in your diet if you're not very careful of the kinds of fluids you choose. Soda is very high in calories and some fruit juices are very high in calories. Apple juice has about 180 calories per 8 ounces, whereas tomato juice has 40. Good Canadian beer has 180 calories, light beer has 100. There is no virtue in drinking whole milk when you have half and half, 2%, or skim milk available. Milk is an excellent food, high in vitamins and calcium. Dairy products in general are excellent.

## **Breast Self-examination for Disabled Females**

Linda M. Hennig

Breast cancer is one of the major illnesses affecting women in the United States today. One out of every eleven women will develop breast cancer in her lifetime. Statistically if we took one out of every eleven women in this audience it would be quite a large number.

Breast self-examination is considered to be the most effective method of detecting early breast cancer. In fact, 95% of all breast cancers are found by women themselves or by their sexual partners. About 84% of breast cancers can be cured if they are detected early.

For women who have experienced a disabling illness or injury, the ability to perform breast self-examinations may be significantly altered.

Are women with disability less susceptible, more susceptible, or the same as the general population with regard to breast cancer? We reviewed the literature and found few articles dealing with breast cancer in disabled women or in fact teaching disabled women how to do a self-examination. We launched a pilot program last year at our rehabilitation center to identify women at high risk to determine if those women who had sensory and motor loss could conduct or perform the standard technique recommended by the American Cancer Society. If they could not use the standard technique, we explored modified techniques for them. Finally, if these women were totally disabled, we tried to teach a family member or significant other person the standard technique.

We were very pleased with the program we launched, and it is now an integral part of our rehabilitation program. The population we worked with primarily included quadriplegics, paraplegics, hemiplegics, patients paralyzed secondary to stroke or head injury, those with rheumatoid arthritis, and some amputees. We performed risk assessments, again using the scale of the American Cancer Society and found that our population predominately fell in the moderate risk category. Among all these patients only two women were totally unable to perform the technique.

In summary my goal in working with women with disability is that if we can have open discussion and look for modified ways of looking at potential health problems then this will lead to an increased awareness on their part and more positive health practices.

## **Exercise for the Cardiovascular System**

Stanley K. Yarnell

General conditioning exercises or aerobic exercises to maintain endurance and maintain the overall tone of the cardiovascular system are good for everyone. Strength and efficiency of the heart in

pumping blood help maintain healthy individual muscle fibers. These healthy fibers effectively use the oxygen they receive. Evidence of maximal use is in the changed enzymes in the muscles when the body engages in general conditioning exercises.

General conditioning exercises are just as good for post-polio survivors as they are for the rest of the population. Probably the best exercise is swimming. It exercises the muscles and stresses the heart appropriately; the buoyancy of the water helps to take some stress off of joints that may otherwise hurt. I would not worry whether the pool is heated or unheated. I do not think that you are going to get that cold in an unheated pool.

If you do not have access to a swimming pool, there are some general conditioning or repetitive exercises which you can learn from a physical therapist. However, all of you who are using your arms to help to compensate for your legs or vice versa or using your trunks are engaged in good general conditioning exercises anyway. I would also emphasize stretching and range of motion and stretching, not just of your limbs, but of your chest wall and abdominal musculature.

What particular applications does exercise have for post-polio survivors and people who have had spinal cord injury? Anyone who has some degree of weakness, whether sitting in a wheelchair or partially ambulatory with some scoliosis, have a tendency to slump over. If they are lying on their side in bed, frequently they are curled up because it is a comfortable position. The chest wall can get tight in that position, and this can lead to further respiratory problems, decreasing compliance, and discomfort. The discomfort may be caused by arthritic changes or joint laxity because joint capsules have become overstretched with time. A useful adjunct to medications such as aspirin and nonsteroidal anti-inflammatory agents, including Motrin, to relieve this discomfort is exercise or the physical manipulations such as heating or icing a joint or some forms of deep heating. Joint mobilization techniques for arthritis can be helpful. For example, mobilizing the sacroiliac joint is a symptomatic pain relief mechanism. Some people can perform these themselves by way of positioning; in other cases attendants can be taught how to do it.

In the event that you aren't able to get from point A to point B without being so exhausted that when you get to point B you are unable to participate or enjoy what you want to do, then you have to look at other ways of getting around. If you have been in a manual chair or have been ambulatory, sometimes using an electric chair is a big energy saver in terms of getting from point A to point B. This is simply a matter of conserving energy and conserving your joints.

# LONG-TERM RESPIRATOR MAINTENANCE SUMMARY

"The early warning signals," said Dr. Alba, "of need for initiating respiratory aid or for increasing aid are increased fatiguability, falling asleep during the day, and increased swelling of the ankles . . . When you have these warnings, you should hook up with a local hospital and have a respiratory evaluation or go back to a center that can do it for you. If you have respiratory involvement, you should have an annual appointment for a checkup."

Dr. Alba described the program at Goldwater Memorial Hospital for eight ventilator-dependent children. To provide stimulation to the children who have little or no interaction with their environment, other children from the area and "grandparents" from a skilled nursing facility are brought in as volunteers. To mainstream education, a trained aide accompanies the child to a nearby school.

"We try," said Dr. Alba, "to give our ALS people as optimal a life as possible. . . . Many of them have been capable of doing some wonderful things . . . We give them and their families a choice of whether or not they want to prolong life with a tracheostomy and to decide whether they want to be resuscitated if they have a mucus plug or cardiac arrest. We try to keep them as well as everyone else. We don't have any additional sympathy because they are dying . . . eventually we are all going to end up dying."

Glossopharyngeal breathing (GPB) is familiarly known as "frog breathing" because it resembles the gulping of the frog. Audrey King described how she had learned GPB after Dr. Alba told her about repeating the word *gup*. As a result, she has significantly increased her vital capacity. Gary McPherson showed a videotape, "Frog Breathing with Gary McPherson."

Dr. Alba has found that persons with spinal cord injury who come from an acute care center with a tracheostomy regard it as an "umbilical cord" and they do not want to learn mouth positive pressure or frog breathing.

Dr. Parsons contrasted the experiences of persons who are ventilator-dependent because of high level spinal cord injury and those who have polio. The mortality for spinal cord injury is high, maybe higher than post-polio persons because of the problems of neurogenic bladder, pressure sores, renal failure, respiratory complications, and disconnection of the mechanical ventilator from the tracheostomy tube. As an example, Craig Hospital discharged 41 spinal cord-injured persons on ventilators between 1974 and 1982 . . . Thirty percent were alive 3 years after the injury and 17%, 5 years

after injury. "There was a clear pattern," he said, "to suggest that those who died spent more time in bed than did the survivors, and those who died spent a great deal less time out of the house than did those who survived."

The efficiency and the specific uses of the various types of respirators/ventilators — iron lung or tank, cuirass, chestpiece or chestshell, plastic wrap or poncho, rocking bed, volume or pressure respirators/ventilators, and pneumobelt — were discussed in detail by Mr. Killam of LIFECARE, Dr. Johnson, and Dr. Alba.

"The mouth," said Dr. Alba, "is one of the best forms of using positive pressure, as I discussed at length in Volume 24 of the *Rehabilitation Gazette* . . . The mouthpiece that is presently the most convenient is the Bennett Lipseal. Adolf Ratzka is working on a form-fitting one that has promise."

Historically, persons disabled by polio in the United States have been tracheostomized less than those in other countries or those disabled by spinal cord injuries. A variety of opinions concerning tracheostomies were presented. A brief summary of some of the opinions expressed: Dr. Alba: "If an individual has repeated difficulty in handling secretions we may have them tracheostomized. . . . From the practical viewpoint, a shortage of caretakers to do postural drainage and suctioning may be the reason for going to a tracheostomy." Dr. Brown: "At the University of Alberta Hospitals 55% of the patients with respiratory poliomyelitis have tracheostomies . . . 39% of these patients have required reestablishment of their tracheostomy within the past 5 years. Notwithstanding the benefits of a secured airway, complications such as localized stomal infection, bronchitis, formation of granulation tissue, and persistence of hypoxemia and hypercapnia can occur." Dr. Johnson: "Too many tracheostomies are done. . . . Even a high quad who has a perfectly normal diaphragm will often be tracheostomized in an emergency room even though he may not need it."

Three comprehensive programs in England, Canada, and Australia were described by Dr. Spencer, Ms. Odynski, and Dr. Newton-John. The three programs include home visits, ventilator maintenance, a team with medical supervision, telephone consultation, and a flexible approach to meeting individual needs.

"Home artificial respiration," said Dr. Spencer, "is totally different from intensive care respiration in the hospital. All the problems of cross infection and other things just do not exist in the home. The

users at home must be the experts in their own care. If they're not, they're not safe to be at home."

Dr. Faure described the psychological advantages and cost-effectiveness of the home care programs for ventilator-dependent children on which she and Dr. Goldberg have worked at The Children's Hospital of Philadelphia and Children's Memorial Hospital in Chicago. These are in the pro-

cess of being expanded around the country.

Bill Tainter added, "The key to living independently with a ventilator is to receive adequate orientation and training about your personal care needs relative to the ventilator. The key to moving out of institutions on your own is the availability of viable options and disabled peer models — the essence of independent living."

## HEALTH MAINTENANCE — VENTILATOR-USERS

### **Ventilator-dependent People — Children, Polio Survivors and Others**

Augusta Alba

Our children are cared for in a rehabilitation setting by a physiatrist, but a pediatrician visits them every two weeks. We have to stimulate these children, who have little or no interaction with their environment. We also have children who are too young to use alarm systems of their own. This requires a greater amount of vigilance on the part of the staff. One of the most challenging problems in the management of these children is the mainstreaming of the child for education. It is also important to use child volunteers.

We need the additional attention of adult volunteers to do homework with the children because they go to a regular school in the hospital as well as the one that is mainstreamed. We also try to encourage voluntary organizations, including the Muscular Dystrophy Association, to give portable suction machines to all of the children. With individual suction machines, if someone wants to take the children off the ward, they can do so at a moment's notice and not worry about suctioning. All of these children are tracheostomized; that is the way that small children have been kept alive from birth, and thus far none can be taken off tracheostomy.

Recently, to improve their growth and development, the children have been "adopted" by "grandparents." These are elderly citizens living at the Mary Manning Walsh Skilled Nursing Facility in Manhattan. They not only send the children gifts, they also come to visit them in person, to sing and so forth with them. The children have also been adopted by a number of local philanthropists — sport teams, individual players, who come and give them what they need — additional ventilators, portable suction machines, and so forth.

Finally, we've arranged early recognition of acute illness in a liaison with the acute pediatric intensive care unit. This allows rapid transfer when they become ill.

We have also addressed the problems of the adolescent, because all these children grow up, and of the problems of those with amyotrophic lateral

sclerosis (ALS). We feel that even if you have a progressive disease, you should experience as optimal a life as possible. We have usually a group of about seven advanced ALS patients in our center. They all have electric wheelchairs until they wish not to be up out of bed.

We give patients and families a choice whether or not they want to prolong life with a tracheostomy. They also have the opportunity to discuss a living will and to decide whether or not they want CPR if they have a mucus clog or something that has caused cardiac arrest. We try to keep them as well as everyone else; we don't have any additional sympathy for them because they are dying. They are kept as useful as the next person. Muscular dystrophy patients, similar to ALS patients, develop weak oral pharyngeal musculature with time, and when the muscular dystrophy becomes far advanced these patients need tracheostomies. We have been able to care for a number of them in the home as well.

Those with muscular dystrophy are most in need of respirators early in the course of their disease. This happens anywhere from the time they are 10, 15, or 20 years old to sometimes as late as 30. However, we have demonstrated in the past 26 years that they can be ventilated and kept alive for many years and go on to independent living like all other disabled people. They are capable of higher education and of benefitting mankind with their experience.

For polio survivors there comes a time, frequently in the late 50s or 60s when there may be some consideration for tracheostomy. Early warning signals of a need for more respiratory aid include increased fatigue, falling asleep during the day, and increased swelling of the ankles, more than ordinary swelling. Other polio patients have no warning of an additional need for more respiratory aid. An individual with chronic obstructive lung disease or intrinsic lung disease in general is frequently very dyspneic, but this is not necessarily true of restrictive lung disease.

We frequently remind them that they should be using more aid. Within the past 2 years at least two

patients have died suddenly because they had never used aid during the day and decided that even though we told them this is what they needed, they knew better than us. I recommend annual appointments if you have respiratory involvement. If you affiliate with a local hospital, they will do your respiratory evaluation or you can come back to a center that can do it for you.

### **Ventilator Care of Spinal Cord Injured Persons**

Kenneth C. Parsons

The care of the ventilator-dependent traumatic quadriplegic can be broken down to spinal cord injured persons and post-polio persons.

Acute polio caused early hospitalization, and many people hospitalized with this diagnosis eventually developed respiratory failure. Some people experienced temporary respiratory failure, and others remained on chronic ventilatory support on a full-time or part-time basis. In contrast, the traumatic quadriplegic with acute respiratory insufficiency often does not survive long enough to reach an acute care hospital. With the increasing availability of people in our population who know how to administer mouth-to-mouth resuscitation, an increasing number of ventilator-dependent patients are reaching acute care hospitals and their lives are being spared. Another population of quadriplegics demonstrate an initial high cervical level of cord injury but are breathing on their own when they arrive at the hospital. However, within hours to days some of these people become ventilator-dependent because increased swelling in the cord causes a higher level injury, which wipes out the nerve supply to the diaphragm, which is at the C-3 and C-4 level of the cervical cord.

Traumatic quadriplegia differs from polio in many ways. Loss of sensation below the level of injury predisposes to pressure sores. In addition, there is evidence to indicate that with a high cervical level spinal cord injury, the sensory loss in the thorax and lungs makes it difficult for the traumatic quadriplegic person to feel "short of breath." Our high level spinal cord injured patients experience sensory deprivation symptoms that may well not have occurred in the post-polio patient who had normal sensation. In addition the normal automatic control of such things as heart rhythm, blood pressure, and sexual function is lost. Normal control over the bladder is lost, causing difficulty in emptying the bladder and predisposing to significant bladder infection and secondary kidney infection as well. In addition to the spinal cord injury, many of these patients have head injury, chest trauma, abdominal trauma, long bone fractures, and spine fractures.

The incidence of ventilator-dependent quadriplegia is somewhat hard to ascertain because many

of these people die before reaching the medical care system. We also know that many ventilator-dependent quadriplegics are never admitted to a full-fledged spinal cord injury rehabilitation program because of a number of geographical and economic factors. If one assumes a minimal incidence of thirty-five new spinal cord injuries per million population per year regardless of the level of injury and we assume that the national population is approximately 220 million, one may estimate approximately 7,700 persons will experience new spinal cord injury per year. An estimated 2% of this population would be ventilator-dependent. Therefore approximately 154 ventilator-dependent quadriplegic patients would be admitted to large spinal cord injury centers per year. However, as I mentioned, this statistic does not account for those who don't survive the initial injury or who aren't transferred to major centers, but do continue living out their days in the acute care setting, usually in the intensive care unit at great expense.

One of the major concerns of a patient with a tracheostomy on a ventilator is the inability to speak. Vocalization, however, is possible with a cuffless tracheostomy tube and a positive pressure ventilator, if the vocal cords are functional. Cuffed tracheostomy tubes have also been developed to allow vocalization. Quadriplegics are usually without hand function, so ventilatory support equipment including positive pressure oral ventilation has not always proven useful. It should be mentioned that positive pressure volume ventilation via tracheostomy requires some sort of monitor or warning device to signal excessive pressure in the system and also to signal when the patient has become disconnected from the ventilator.

I have discussed glossopharyngeal breathing with two experienced spinal cord injury physicians who also cared for polio patients in the past. They both reported that they did not recall being able to successfully teach traumatic quadriplegics glossopharyngeal breathing so as to allow their patients to be temporarily free of the ventilator. It's not entirely clear why traumatic quadriplegics do less well with this technique than post-polio victims, but it may relate to the sensory problems in the lungs and thorax or the presence of the tracheostomy.

There are significant similarities between ventilator-dependent quadriplegics and ventilator-dependent polio patients. First, the number of people who are chronically ventilator-dependent is probably small, considering the larger number of people affected by either condition. Second, high mortality has been observed in both populations. This long-term mortality is probably higher in traumatic quadriplegics because of the complications of neurogenic bladder and kidney function deteriora-



tion. Also, mortality soon after injury for traumatic ventilator-dependent quadriplegics is quite high. Costs for care in the acute setting and for home placement are very high for both patient groups. High technology definitely results in high costs. Home placement with attendants has proven to be cost-effective in both diagnostic groups and also is optimal for psychosocial recovery from the condition. However, obtaining funding for equipment and home modifications continues to be a severe problem with spinal cord injured patients, as was observed with the polio patients before the involvement of the National Foundation — March of Dimes.

Another significant similarity is that optimal care is delivered best at regional centers for respiratory care. The factors are several and include the experience of the staff, peer support as role models, and appropriate programs for preparation of the family to receive the patient at home again.

Another similarity we recently noticed in ventilator-dependent quadriplegics is the development of late respiratory compromise in patients who had been weaned to ventilator-independent status and subsequently went back on ventilatory support after complications or perhaps after late deterioration of diaphragm strength. This may relate in some fashion to the "post-polio syndrome," or some other neurological effect of aging.

Some centers are using the mechanical ventilation devices that were developed for polio. The Santa Clara Valley Rehabilitation Center has some experience with the use of the pneumo-belt in San Jose, California. In Australia John Yeo has used the cuirass or chest shell ventilator with some success. Recently in a respiratory therapy journal there was a report of successful use of the iron lung at the Dallas Rehabilitation Institute. Sensory loss of the skin may limit the tolerance and safety of these devices.

The experience at Craig Hospital with ventilator-dependent quadriplegics should be briefly reviewed. Between 1974 and 1982 forty-one patients were discharged on ventilators. Thirty-four of these patients were studied in a follow-up survey. Fourteen of the thirty-four had expired. Overall only 30% of people discharged on ventilators full-time were still alive 3 years after injury and 17% 5 years after injury. Seven of the deaths were clearly related to pulmonary problems. One died of cancer of the lung, one died of stroke, and one died of "lack of will." Two other patients were reported to have "decided to die." Seventy-five percent of the patients discharged went to their homes, and the other 25% went to extended care facilities. There was a clear pattern that suggested that those who died spent more time in bed than did the survivors, and those who died spent a great deal less time out of the house than did those who survived. The attitude of the survivors was positive about living

in 80% of patients surveyed; only 20% of the survivors were reported as being negative about living on the ventilator.

In conclusion, among spinal cord injured individuals, there are still few patients each year who require acute ventilatory support and who will remain chronically ventilator-dependent for the rest of their life. Spinal cord injury mortality among those who are ventilator dependent is very high both during hospitalization and after discharge. It may be higher than among post-polio patients because of the problems of neurogenic bladder, pressure sores, renal failure, respiratory complications, and disconnection of the mechanical ventilator from the tracheostomy tube.

An appropriate preadmission screening program with on-site consultation by a spinal cord injury physician and an administrative person has made it possible for Craig Hospital to serve many ventilator-dependent quadriplegic patients from all over the country. Funding problems are decreased when the information is presented directly to the appropriate insurance carrier before transfer to the rehabilitation center. Guaranteed funding is a prerequisite for transfer, as is an appropriate discharge plan.

Aging effects in spinal cord injury are not as well understood as are those which have been described for post-polio individuals. However, there is evidence to suggest that some spinal cord injured patients who have been weaned from the ventilator may eventually become ventilator-dependent once again.

Time does not permit a detailed discussion of costs of equipment items and hospital care. Neither am I able to discuss the use of electrical stimulation of the phrenic nerves to elicit diaphragmatic breathing. Your polio rehabilitation experiences are the basis for modern spinal cord injury rehabilitation.

**Glossopharyngeal Breathing** Gary McPherson  
Frog breathing is not new. It should not be restricted to people who have polio because it has a tremendous future for people with spinal cord injury and other upper respiratory disabilities.

Frog breathing involves the use of the throat and posterior tongue muscles to hold the breath once you have taken it. A vital capacity three to four times the tidal volume can be achieved with frog breathing. You can take a breath through your nose or your mouth, as normally done. You frog breathe by holding your breath and adding to it with gulps of air. I start by taking a neck breath with my accessory muscles. I get about 150 cc of air in my lungs and then I hold it. Next I open my mouth and draw my tongue and throat muscles down to allow air to enter my throat. Then I close my mouth and force the air down my throat with my tongue and throat

muscles while I hold my breath. I call this inspiration of air a stroke, and I get about 50 to 75 cc of air into my lungs with each stroke. Since my average breath is about 800 cc and I started with 150 from my neck breath, I need about ten strokes per breath. Sitting and talking like this I need about eighty breaths per minute. First, I hold my breath. Then I open my mouth to let air in, then close it. I force it down my throat into my lungs. I hold it there while I open my mouth for the next stroke. Only when I have taken several strokes do I release my breath. It takes a lot of practice, and your throat and tongue muscles need to be active.

The technical description of glossopharyngeal breathing sounds like this: A mouthful or throatful of air is taken by depressing the jaw, the floor of the mouth, the tongue, and the whole pharyngeal body to increase the volume of space in the mouth and throat. There is also a widening of the pharynx. During this first step the larynx is closed. During the second step the lips are closed and the soft palate is raised to trap the air in the mouth. Next, the larynx is opened and in a progressive manner the tongue pushes the air from the front of the mouth to the back and through the open larynx to the lungs. The movement of air is aided by raising the floor of the mouth, the jaw, and the larynx, and there is a narrowing of the pharynx. Finally, the larynx is closed again and the air that was forced into the lungs is trapped there. All is ready to repeat the cycle and add more air to the reserve building in the lungs.

Frog breathing through the nasopharyngeal airway is very similar except you draw air in through your nose instead of your mouth. However, the stroke volume is somewhat reduced. The advantages of frog breathing through the nose are that it provides natural humidification, it eliminates the dryness of the mouth that occurs when mouth breathing, and aesthetically it is less obvious to the people around you. The muscles used in frog breathing need to be exercised regularly to gain strength and efficiency.

Frog breathing allows people to live independently during the day away from the ventilator, allows the person to generate a good cough, and is a supplementary type of ventilation that requires no equipment, an acquired skill that anyone can learn. In case of an emergency, when for some reason mechanical ventilation is stopped, the person can rest comfortably knowing that he is ultimately dependent on himself, not on a machine. It can be very dangerous for those people who have tracheostomies if they cannot cover the opening with a finger or a well-secured plug. It is not possible to frog breathe with an open tracheostomy, and if you are using a tracheostomy there is still some leakage around the opening. This makes it a little

more difficult, but it is still possible to frog breathe with a tracheostomy.

Frog breathing was used in the polio epidemic during the early 1950s by patients who learned how to breathe independently and shared this method with others. Frog breathing is still mainly used by people whose respiratory systems have been disrupted by polio, but it is a breathing method that can be used by most people with chest muscle paralysis or reduced lung capacity who still retain the ability to use the tongue, throat, and neck muscles. Frog breathing in many cases, such as among high level quadriplegics, may be useful in helping to build a volume of air to support a deep cough, which could minimize congestion, particularly when a person has a cold or other respiratory complications. I have found that in exchange for the time and effort required to learn this skill, I have freedom and independence from my ventilator for a few minutes or several hours. Without my ventilator I'd say my activities are limitless.

### **Further Notes on Glossopharyngeal Breathing**

Audrey J. King

Those who have reduced capacities may find it a little harder to learn glossopharyngeal breathing because they guard the air they have and don't relax their chests to allow air in. Also if you say "gup" you need air coming out of your lungs to voice the word, and that's the opposite of what you're trying to do, so that gets a little confusing. You don't get immediate feedback. It takes about eight or so successful "gups" before you can feel your chest expanding and know that you're doing the right thing, but once you get this feedback, you really are on to it. I think another major barrier is the embarrassment you feel; you really do feel silly. Persistence and motivation are mandatory.

I think the best way to teach somebody is by having that person imitate the cluck sound that you make in the back of your throat. Then once you're copying the cluck sound, if you form the word "gup" but don't actually voice it, so that you have the lip and mouth movement, you can feel the air going in fairly quickly.

Frog breathing can be done anywhere, anytime. It is great for fatigue, for coughing, and for getting a deep breath.

### **Motivation and Glossopharyngeal Breathing**

Augusta Alba

I found with my spinal cord injury patients that they don't want to learn glossopharyngeal breathing; they don't want to learn mouth positive pressure. I call the hook-up to the tracheostomy at the acute care center an umbilical cord, and there is no incentive to get away from this because it is very comfortable — you don't even have to think about

breathing any longer. I can't motivate them to learn mouth positive pressure, although there is no reason why they can't.

If you have the secret of motivation, you have the

secret of life. I watched these people who do it here. We aren't talking about minutes of free time, we're talking about a day of free time if you learn to do it properly.

## RESPIRATORS/VENTILATORS

### Oral Positive Pressure

Augusta Alba

All forms of airway ventilators are positive pressure ventilators or pressure ventilators. We consider the mouth one of the best forms of using a positive pressure simply because you can use glossopharyngeal breathing concomitantly with mouth positive pressure breathing. The airway breathing can give you a tidal volume as large as the volume you can receive in a body ventilator, iron lung, and poncho. No other body ventilator, and that includes the Pneumobelt, the chest respirator, and the rocking bed, can give you the same large amount of volume. The older the ventilator-dependent individual becomes, the more he requires a ventilator that can give him a larger volume.

Basically mouthpieces of many shapes and forms can be used. The one that is most convenient both for sitting and lying down has some degree of angulation. For years at Goldwater, and now throughout the country, we have been using a Bennett Lipseal with a straight mouthpiece, either with a simple plastic strap with a hook that attaches behind your mastoid or canvas straps above and below the ears with Velcro closure. This allows you to use the mouth positive pressure when you are lying down and when you fall asleep. It is a conditioned reflex.

Acute toxic metabolic states can occur with certain disease conditions, or infections can be contracted in which you have a decreased state of consciousness. In these circumstances you should be tracheostomized, at least temporarily, if not permanently. One young man went through a period of renal failure and needed to be tracheostomized because he was in a state of delirium. Now, months later, he has peritoneal dialysis on a regular basis and has decided to take his tracheostomy tube out. He's back to frog breathing, although he no longer can do it for prolonged periods of time.

About 12 years ago we did a study at Goldwater that showed there are people who cannot breathe longer than 5 minutes at a time with frog breathing. This occurs in intrinsic lung disease and possibly in severe kyphoscoliosis or in repeated bouts of pneumonia or other complications. If you don't have normal lungs, no matter how hard you try, it may not be possible because your blood oxygen level drops too rapidly for you to use this as your only method of breathing. When the saturation drops to 85%, you will want to use some form of

breathing other than frog breathing by itself.

If an individual has repeated difficulty in handling secretions, we may recommend tracheostomy. Sometimes an individual doesn't have caretakers available to perform the postural drainage and chest physical therapy needed. If there have been recurrent bouts of atelectasis or of acute pneumonia with a prolonged period of incubation and secretions that will be present for several weeks, we may decide to tracheostomize. Aspiration also occurs when you may change from mouth positive pressure to tracheostomy positive pressure.

Dr. Adolph Ratzka is working on a form-fitting mask, which he hopes to develop commercially. He is also working on a form-fitting mouthpiece.

Nasal CPAP (positive pressure ventilation) has now been given successfully with a nasal mask, instead of mouth positive pressure ventilation, not only during the day but possibly in your sleep. Just as you learn to close your soft palate when you are breathing through your mouth, you can learn to close your mouth when you are breathing through your nose with positive pressure in sleep. Occasionally there is a problem with loosening of the lower incisors from the use of the mouth positive pressure mouthpiece. This may require extraction and the fitting of a permanent partial plate.

### Plastic Wrap

Ernest W. Johnson

The types of polio that are going to require ventilation we used to divide into abortive, nonparalytic, and paralytic. Abortive meant only the gastrointestinal phase of the disease was present; it never entered the central nervous system. Most of us had this type of polio, with no residual effects. The nonparalytic type does not involve functional weakness. If the disease invades the central nervous system, technically it is paralytic, even if there is no functional weakness. If more sophisticated tests were used, we could perhaps see some weakness. The paralytic variety is further divided into bulbar and spinal types. Bulbar polio has to do with muscles of the pharynx. It is often mistakenly thought that people on ventilators have bulbar polio, but they do not. They have high spinal polio. Spinal polio is divided into the high spinal type, in which ventilators are almost always necessary, and the low spinal type which involved the lower extremities.

The breathing muscle, the diaphragm, is responsible for about 55% of our vital capacity. If we lose control over the diaphragm, as in the high spinal type of polio, we might need ventilation during the acute phase. However, if we have control over our intercostal muscles, our chest muscles, and what we call our accessory neck muscles, we can still probably breathe after the acute phase is over, because we still have 40% ventilation.

How do we breathe? Basically we develop a negative pressure within the lungs so that the atmospheric pressure will force air into the lung. If the atmospheric pressure is 760 mm Hg or cm H<sub>2</sub>O, and we lower our diaphragm and raise our ribs so that the space in our chest lowers the pressure about 3 or 4 cm, air comes in. That is the principle of the plastic wrap ventilator or the iron lung. It deals with the ambient pressure, the pressure around the body. This pressure is reduced by either putting the person in an iron lung or putting the person in this plastic wrap.

The wrap (Dr. Alba calls it a poncho) is hooked up to a pump so that the pressure around the body will be considerably less. If it is at 20 cm H<sub>2</sub>O negative pressure around the body, the pressure in the air passages would be -3 or -4, so air would come in the mouth. The so-called negative pressure ventilators, like the plastic wrap, are no different from positive pressure by mouth as Dr. Alba was describing. Pressure higher than atmospheric can be applied at the mouth to force air in, or pressure can be withdrawn from around the body so that atmospheric pressure is then positive. The physiological effects are the same.

With respect to the efficiency of the various ventilators, this has been well documented over the years. The iron lung or the tank respirator is considered 100% efficient. The next most efficient is probably the plastic wrap, which is close to 100% and is for people who are using positive pressure during the day. I don't think there is any reason for using an iron lung any more, except if you don't have the Thompson AC-driven pump. The advantage to the plastic wrap, of course, is that it doesn't have anything in contact with the skin. It would be nice to use in spinal cord injury, and we do use it because people with spinal cord injury don't have surface sensation.

Next is a chest abdomen cuirass. It is about 60% as efficient as the iron lung, if it is fitted properly. At about 50% efficiency is the Pneumobelt. The unfortunate aspect of the Pneumobelt is that you have to be almost sitting at about 45 degrees for it to work because it works by pushing the diaphragm up and then using active expiration and passive inspiration. It is a different principle, but it works very nicely sitting in a chair.

Finally, the least efficient are the rocking bed and

the chest respirator. The chest shell just covers the chest, and we rarely use them any more. Most of the cuirass types are chest-abdomen respirators, that is they cover the abdomen too. We have the Monaghan and the turtle types.

The plastic wrap respirator has the advantage of not causing any irritation around the skin. The new plastic wrap has a zipper so it is convenient and easy to put on. This type is very close to natural breathing.

I would recommend the use of positive pressure by mouth during the day and the plastic wrap at night.

I feel there has been a general reluctance to indict the tracheostomy by our group, but I will indict it because I think it's very often an unnecessary operation. It is often done because the person arrives at the emergency room and no one knows what to do. I think our technology today is such that we ought not to have so many tracheostomies. If you have one, I think you can practice closing it with the Plum button. Fred Plum was one of the original respiratory center directors, a neurologist, and became interested in this. He devised this button so that you could close off a tracheostomy without compromising the lumen of the trachea.

#### **Tracheostomies and Respiratory Polio: The University of Alberta Hospitals Experience (1976-1982)**

Neil E. Brown

Since 1953 the University of Alberta Hospitals have served as the major referral and treatment center in the Province of Alberta for patients with respiratory polio. In this paper the recent experience with tracheostomies in this group of patients at our center will be discussed. Emphasis will be placed on the indications for tracheostomy and the complications of such intervention.

In the 7-year interval, 1976 to 1982, forty-two patients with respiratory polio have been treated. (Table 1.) The ten patients who permanently reside in the hospital all require ventilatory assistance, and the majority have tracheostomies. The other thirty-two patients live in the community but may require periodic hospitalizations for treatment of acute medical problems. Most of these outpatients require some form of ventilatory assistance, and the majority of these have had tracheostomies. Seven of the twenty-three patients with tracheostomies have required establishment of their tracheostomy during the last 5 years.

In Table 2 the indication for tracheostomy either at the time of initial infection with the polio virus or at a later date are listed. The majority of patients requiring tracheostomy were hypoventilating as a result of central polio, neuromuscular weakness, severe scoliosis, or a combination of these. In most instances other methods of ventilatory assistance

were tried without success in restoring ventilation to normal. Two patients with bulbar polio developed upper airway obstruction 25 years after the acute polio and required tracheotomies to bypass the life-threatening obstructions. Finally, six patients had tracheotomies to control the secretions associated with pneumonia.

Three cases will be presented to illustrate a few of the reasons for performing a tracheotomy today.

**CASE #1:** Mrs. L.E. Age 63  
Neuromuscular Weakness

This 63-year-old woman contracted respiratory and paralytic polio in 1953. She initially required a tracheostomy for control of secretions but by 1955 was breathing well without ventilatory assistance and was clearing secretions adequately, so that the tracheostomy stoma was allowed to close. In 1969 she developed pneumonia and required positive pressure ventilatory assistance for 1 month. The stoma was subsequently closed when she once again was able to handle secretions. In 1980 the patient was seen again, this time with weight gain resulting from right-sided heart failure, acute onset of confusion, and hypoventilatory respiratory failure thought to be caused by respiratory muscle weakness. The patient was placed on positive pressure ventilation with resultant correction of the hypoventilation and restoration of normal cardiac and cerebral function. She was discharged using nocturnal positive pressure ventilation and has remained well. Some of the patient's pulmonary function measurements are listed in Table 3.

**CASE #2:** Mr. A.G. Age 49  
Respiratory Infection

This 49-year-old man with respiratory and paralytic polio was initially treated in 1953 in the iron lung. Subsequent respiratory assistance was not required until 1979 when the patient was treated in the intensive care unit for pneumonia and respiratory failure. He was discharged home using a rocking bed for nocturnal ventilation. Because of progressive hypoxemia, nocturnal oxygen therapy was instituted in 1981. A few months later the patient once again required hospitalization in the intensive care unit for treatment of respiratory failure and secretion control in association with pneumonia. Positive pressure ventilation was required, and a tracheostomy was established. On discharge from the hospital he was maintained on nocturnal ventilation using a positive pressure ventilator. His previous hypoxemia and hypercapnia, present for at least 2 years, was corrected (Table 4).

**CASE #3:** Mr. M.D. Age 40  
Upper Airway Obstruction

This 40-year-old man required ventilatory assistance and tracheostomy in 1953 for bulbar polio. In 1965 he underwent an unsuccessful surgical re-

pair of his pharynx to correct his dysphonia (impaired speech). In February 1981 the patient reported a 2 year history of increasing fatigue. Apart from a moderate scoliosis of his cervical spine, dysphonia, and decrease in chest expansion, no other physical abnormalities were present. He had evidence on pulmonary function testing of severe inspiratory airflow obstruction and on arterial blood gas measurement of moderate hypercapnia. Bronchoscopic examination revealed bilateral vocal cord paralysis with glottic stenosis. Six months later his condition deteriorated following the retention of secretions associated with an upper respiratory tract infection. He could not sleep at night and had daytime somnolence. On examination he was cyanotic, had inspiratory stridor, and displayed a marked decrease in air entry. Once again there was severe inspiratory airflow obstruction. Arterial blood gas measurements taken breathing room air showed impairment ( $\text{PaO}_2$ , 37 mm Hg;  $\text{PaCO}_2$ , 62 mm Hg). Following an emergency tracheotomy his condition rapidly improved, and by the time of discharge from the hospital 1 month later, his arterial blood gas levels obtained breathing on his own through the tracheostomy had improved to  $\text{PaO}_2$ , 75 mm·Hg and  $\text{PaCO}_2$ , 35 mm Hg.

Tracheotomies were performed in seven of the twenty-three patients (30%) with respiratory polio 25 years or more after the initial infection with polio virus. Review of patient records indicates that all seven had required a tracheostomy during their initial infection. Three patients had pneumonia, two patients had upper airway obstruction, and two patients had chronic respiratory failure with secondary heart failure as the primary reason for reestablishing the tracheostomy. All seven patients had symptoms of chronic hypoventilation predating the tracheostomy.

The symptoms of chronic hypoventilation are the result of the presence of hypoxemia and/or hypercapnia (Table 5). The onset of symptoms was usually insidious and difficult to recognize by the patient, family, friends, or medical personnel. Fatigue, weight gain resulting from fluid retention (edema), the onset of high blood pressure, and personality changes were frequently noted. Nocturnal insomnia and daytime somnolence were also observed. Few patients complained of shortness of breath if hypoventilation alone was present. Infection, secretions, and atelectasis were usually associated in those with shortness of breath.

Although most patients who require a tracheostomy will benefit, this is not without problems, both acute and chronic (Table 6). Post-tracheostomy superficial stomal infections with *Staphylococcus aureus* are not uncommon. A few patients have tracheas colonized by this organism and require long-term suppressant antibio-

tics. Failure to provide adequate humidification may lead to tracheobronchitis and an increased rate of lower respiratory tract bacterial infections. A few patients who have used fenestrated tracheostomy tubes have developed exuberant granulation tissue growing into the fenestration. Similarly, granulation tissue can form at the stomal site because of tube irritation of the healing mucosa. If granulation tissue formation is severe, revision of the tracheostomy and the use of unfenestrated tubes will be required. Even with a tube in place, adequate ventilation is not guaranteed if the cuff is not inflated or if the cuff leaks, in those patients in whom a cuffed tracheostomy tube is necessary to maintain adequate volumes.

**CONCLUSION:** At the University of Alberta Hospitals, 55% of the patients with respiratory polio have tracheostomies for control of secretions, relief of upper airway obstruction, or treatment of refractory hypoventilation when used with positive pressure ventilation. Of these patients 30% have required the reestablishment of their tracheostomy within the past 5 years. Notwithstanding the benefits of a secured airway, complications such as localized stomal infection, bronchitis, formation of granulation tissue, and persistence of hypoxemia and hypercapnia can occur.

Table 1.  
**Incidence of respiratory polio at University of Alberta Hospital (1976-1982)**

	Number	Number with ventilatory assistance	Number with *tracheostomy
Inpatients	10	10	6
Outpatients	32	23	17
Total	42	33	23

\*Includes ventilation by rocking bed, pneumobelt, curaiss, and positive pressure ventilator via mouthpiece or tracheostomy.

Table 2.  
**Respiratory polio tracheostomy (23 patients)**

Indications*	Number
1. Hypoventilation	
a. Central	8
b. Neuromuscular weakness	16
c. Scoliosis	2
2. Upper airway occlusion	2
3. Secretion control	6

\*Some patients had more than one indication.

Table 3.  
**Case 1**

Pulmonary function			
Date	Vital capacity: % predicted	PaO <sub>2</sub> (mm Hg)	PaCO <sub>2</sub> (mm Hg)
1963	74	83	40
1979	26	56	48
1980	26	38	46
Ventilator			
1983	26	83	31

Table 4.  
**Case 2**

Arterial blood gas values			
Date	Mode	PaO <sub>2</sub> (mm Hg)	PaCO <sub>2</sub> (mm Hg)
May 1979	Spontaneous	41	59
June 1979	Rocking bed	68	42
June 1979	48 hr. off rocking bed	68	59
January 1981	Rocking bed	46	49
	Rocking bed plus nocturnal O <sub>2</sub>	62	53
March 1981	Tracheostomy-ventilator	72	35

Table 5.  
**Symptoms of chronic hypoventilation (hypoxemia and hypercapnia)**

Type	Symptom
Systemic	Fatigue, weight gain
Respiratory	Dyspnea
Cardiac	Tachycardia, palpitations, hypertension, edema
Renal	Nocturnal frequency
Neurological	Morning headaches, irritability, insomnia, daytime somnolence, inability to concentrate, forgetfulness

Table 6.  
**Complications of tracheostomy**

Infection at the stomal site
Tracheobronchitis (lack of humidity, infection)
Formation of granulation tissue
Hypoventilation (uncuffed tube, cuff leak)

### Swedish Face Mask

Adolf Ratzka

Gary McPherson uses a form-fitted bite piece done by a dental technician in dental acrylic. With Gary's piece, if the pressure is on, you have to fight with two leaks: one through the lips and the second through the nose. The problem of the lip seal is that when the pressure comes on, the lips are pushed against the inside of the shield and there is a seal there. My mask does not have a perfect seal either; there is a little bit of saliva that I covered with some absorbent material. I get rid of the saliva problem, although it doesn't really bother me.

The second leak is through the nose. On my mask, I extended the shield over to the nose. When the air pressure comes in, the nostrils are inflated and are pushed against the inside of the shield. Again, it is not a perfect seal, but it doesn't really matter because the volume ventilators today deliver so much air that is not the problem and the noise doesn't bother me either. There is hardly a noise there.

My face mask which covers both mouth and nose and is held in place by my head gear. The mask sits on both nose and mouth and is cushioned inside with leather. Leather is a very good material for this because it absorbs moisture, so when the pressure is applied, the leather inside is pushed toward the

skin and makes a seal there. Now we use some sort of plastic and even some metal parts. We'd like to have the whole thing in translucent plastic, which is much more lightweight. I hope in 1 or 2 years it will be commercially available.

### **Respiratory Equipment**

Eric Killam

Thompson Respiration Products and J. H. Emerson & Co., the manufacturers of the original iron lung, are manufacturing wraps in two different styles: the poncho wrap, which is a half wrap, and a full body wrap. LIFECARE is also manufacturing a full body wrap.

The wraps now are gaining wide respectability across the country. There has recently been a lot of publicity about the effectiveness of wraps and a lot of different application sensors. I think this shows a trend toward the rehabilitative issue of independent living. I think this is a very positive issue.

Chest shells are still being manufactured by two or three companies. LIFECARE is manufacturing chest shells and cuirasses. Thompson is manufacturing chest shells and there are also independent companies around the United States who are doing custom shell work, using body casts that are made in the home or in orthopedic-type jobs.

The negative pressure ventilators that are used to power wraps and shells can be obtained from Emerson and the chest respirator from Thompson. The Thompson negative pressure ventilator offers both negative and positive pressures. There are various alarms for patient safety and also proximal airway sensing potential. Both of the negative pressure ventilators just mentioned are very reliable

pieces of equipment, and they have both been designed for home application.

Iron lungs and rocking beds are still being manufactured by Emerson. They manufacture these on a limited supply and through order only.

Many of you have seen Sunny Weingarten's quarter lung. This is a recent development and is a very positive step as far as portable iron lung equipment.

Positive volume ventilators are being manufactured by numerous companies. Life Products is manufacturing the LP3 and LP4, which are both portable and very reliable units. Thompson produces the M25 and the M3000 XA. Both of these units offer variable I:E ratios and assist capabilities. The M3000 XA also features a sigh mode. LIFECARE currently manufactures the PVV and will soon be releasing a PLV-100. The PLV-100 is designed for home use, as is the PVV and will feature IMV capabilities, variable I:E ratios, and proximal airway pressure sensing and assist.

All of the equipment I have mentioned is good, up-to-date equipment. Many patients who are using ventilators at home are doing just fine on equipment manufactured during the polio era, but manufacturers feel pressure to develop equipment to suit the needs of various types of individuals. Cost and effectiveness are important considerations. Emerson is located in Boston, Massachusetts. Sunny Weingarten, Life Products, Thompson, and LIFECARE are all in the Denver area. Sunny has a data sheet on his Porta Lung, Thompson has data sheets on their equipment, and LIFECARE would be glad to send data sheets on all of our equipment.

## **HOME CARE PROGRAMS FOR VENTILATOR-USERS**

### **Home maintenance service**

G.T. Spencer

I started supporting people using ventilators at home in 1968. I did it because I happened to inherit 18 people using ventilators who had had polio for many years. Rather than medicine, it was quite clear that what those 18 people wanted was some sort of maintenance arrangement for their equipment at home. I went round and I saw them all in their homes for a day or two so I could see how they managed. The day before I came here I discovered that we now have 167 people at home with some type of mechanical breathing aid. Most are people who have had polio, but that group is declining in proportion. There are a number of other people with other illnesses who need ventilators at home; the variety is constantly increasing.

Since we began, two other hospitals have started to use our home maintenance services. A professor of chest medicine, David Flindley, who works in Edinburgh, is trying to start a somewhat similar ser-

vice to combine with the service he already runs for maintaining home oxygen concentrators.

We have three vans in which we can put ventilators. These vans now travel over 200,000 miles a year, even in a small country like England. We have four technicians and a senior nursing sister, half of whose time is spent making home visits to people who use ventilators. We have to maintain this service for the whole country because local hospitals do not have enough people using ventilators in their areas to be able to maintain a knowledgeable staff available around the clock. People question whether it is reasonable for this sort of service to remain hospital-based. Shouldn't it be based locally? There is a problem of responsibility because there is no doubt that maintaining breathing apparatus in the house is quite a responsible job. If not handled correctly, it can quite easily cause serious disaster if not death, and the question of responsibility remains. It has seemed easier in

England for this responsibility to be taken by the hospital that actually employs and looks after the technicians who do the service. It would have been possible to use manufacturers' maintenance contracts to look after the ventilators, at least for British-made equipment. We have found this to be more expensive, and the manufacturers, perhaps surprisingly, seem to like our way of doing things because they feel they never make enough money on domiciliary maintenance contracts to cover the cost of sending experienced engineers to look after the equipment. They're quite happy for our technicians to stay at their factory for a week or two and attend classes so they can be taught about the machinery. This also helps in getting spare parts, because our technicians can ring up somebody they know and get what they want.

Our service is not perfect. The salaries we are allowed to pay these technicians aren't as high as they should be, and it is a 24-hour service. Two of the technicians have been with us for over 10 years, but it's difficult to keep people who know all the patients. Our original idea was not to repair at home but just to swap and repair at the base unit. But our numbers have grown too fast, and we've never been able to build up enough spare machines to operate on that principle. I think it's perhaps interesting that although we offer an emergency 24-hour service, there are very few emergency calls. Most of our service is regular planned maintenance that can be done as routine; we regard an emergency call as a failure on our part. For the people who are ventilator-dependent, in our grades 3 and 4, we also provide a portable electric generator for use at home.

People from the States who would like to come to England, bringing ventilators, should know that our voltage is different. It is 240-volt, 50-cycle. If you bring a 60-cycle machine, you will need not only a transformer to step up the voltage, but a different sized electrical plug. You will also find that the machine works at 5/6 of its capability.

This all applies not only to England but also to most of Europe, where, although the voltage is a little lower, about 220, there are still mostly 50-cycle mains. There are many places in Europe where the main's electrical supply is not totally reliable, and it is often cut off at night. We do have transformers and a couple of Monaghan 170-cycle ventilators that we can lend out for holidays. And if any of you do travel to England and want to borrow or obtain advice about this, contact us in advance, so that we can try to meet your needs. We have to operate on a first-come first-served basis.

## **Respiratory Home Care — University of Alberta Hospitals** Theresa M. Fortunaso

In May 1954 the University of Alberta Hospital was declared the provincial care facility for polio. Polio Home Care came into existence to meet the needs, both physical and emotional, of patients with respiratory polio. In June 1974 Respiratory Home Care was established as a 3-year pilot project considering the needs of respiratory patients with polio and chronic lung disease. The overall objective was to "assist individuals to live a relatively normal life within the confines of their disease." With the program, individuals no longer required permanent hospitalization. This paper will present Respiratory Home Care and the program established for clients with polio.

The Respiratory Home Care program consists of a multidisciplinary team of professionals, including the following: medical director, business manager/technical advisor, secretary, nurse, respiratory therapists, physiotherapists, social worker.

The role of each member of the team is that of partnership with his or her co-worker. All team members are capable of supervising medications, solving minor problems with respiratory therapy equipment, and performing physiotherapy techniques as required.

On each home visit all team members perform a total assessment of the client, including vital signs, checking for edema, reviewing medications, auscultating the chest, and reporting any changes to his or her physician. The team has access to and can use the University of Alberta Hospitals, including the radiology, laboratory, dietary, psychology, and pulmonary function departments and the pharmacy.

Presently our follow-up group totals 130 clients, 28 of whom are post-polio survivors with respiratory deterioration. Of these 28 polio clients we have:

- 3 clients with oxygen: gas tanks, liquid canisters, or nitrogen extractors
- 15 clients with tracheostomies
- 20 clients on continuous or assisted respiration: 12 use ventilators with tracheostomies, 4 use ventilators with special mouthpieces, 12 use rocking beds, 1 uses a pneumo belt, 3 use chest pieces, (iron lungs are used for acute care during hospital admissions)
- 6 clients with treatment equipment: 2 use coflators and 7 use aerosol therapy (4 IPPB, 1 small volume nebulizer 2 large volume nebulizers).

Because of the specific medical care required by these people, the respiratory therapist's role has been an active one. Responsibilities consist of the following:

- Assessment — identify respiratory therapy needs and ordering equipment and supplies.



- Education — conduct home treatment program, emphasize the patient's responsibility to assume a role in his own care, stress the responsibility of the family or in-home care worker to be aware and assist in all aspects of care.
- Follow-up — treat the client in the home and provide quality control of respiratory equipment.
- Consultation — teach other professionals, coordinate with community home care agencies, and act as a consultant to post-polio patients and families in the province of Alberta.

**ASSESSMENT.** The following aspects of the patient's respiratory and physical status are assessed:

- Respiratory assessment — breathing patterns, auscultation, sputum or tracheal aspirations, vitalometry.
- Equipment assessment — respiratory needs, including continuous or assisted ventilators, tracheostomy supplies, suction apparatus, and treatment therapies.
- Activities of daily living — assessment of the problems identified and referral to our physiotherapist.
- Extensive medication requirement — referrals to our program nurses.

Following the assessment, a treatment program is established with immediate and long-term goals.

- Immediate goals are basic survival skills.
- Long-term goals and expectations of client and therapist must be realistic and acceptable to both. Beyond perfecting the survival skills, patients are already functioning at maximum capacity. However, continuing independence may always remain as a lifetime goal.

**EDUCATION.** In our experience with chronic respiratory illness we recognize the importance of education in preventive care. Education may be structured for an individual or a group, where lectures and practice sessions are presented on anatomy and physiology of the respiratory system, lung irritants, warning signs, respiratory therapy and physiotherapy, medications, and diet. These lectures will aid the client in giving self-care and establishing a home treatment program.

**FOLLOW-UP.** The client is routinely visited in the home by the respiratory therapist. Tracheostomy tubes are changed as well as breathing circuits on the ventilator and/or treatment equipment. Vitalometry results are reviewed two or three times each year, and ventilator use is monitored to maintain quality control of the equipment. Techniques are reviewed with the client and his or her health aid in the home setting, assuring the therapist that all procedures are carried out properly and safely.

**CONSULTATION ROLE.** All members of our Respiratory Home Care team act as resource personnel to other health care professionals, both in the city of Edmonton and in surrounding rural areas.

Respiratory Home Care is a rewarding experience. It creates a liaison between hospital and home, teaching team members and clients independence, responsibility, and respect for themselves and others.

### **An Australian Respiratory Care Unit**

Hugh Newton-John

Fairfield Hospital is the only long-term respirator unit in Australia. The first big epidemic of polio was in 1937-1938, and the hospital admitted 1,300 patients then. In the 50s the average number was about 160 per year. In the last 15 years we've only had 5 new cases of polio. There were about 300 respirator cases treated in the hospital between 1937 and 1957. There are 2 who have remained there since the early 1950s. Quite a few others have died.

There are about 40 ventilator-dependent people in Victoria. Most of them are not in hospitals.

Medical care and equipment are basically free for all polio patients. There is a polio branch of the Health Department that was set up in the 1950s and originally consisted of a number of physicians, social workers, and physiotherapists. Now it's running down and it is increasingly difficult for us to find equipment in home support. Our unit has evolved out of necessity.

I began work at Fairfield about 12 years ago and have been looking after the post-polio survivors ever since. About half of our residents now have other neuromuscular diseases, such as muscular dystrophy. There are 20 openings for beds but most of them are actually filled with iron lungs. Our iron lungs are not iron at all. We make our tank ventilators out of plywood, seven-ply and quite sturdy. They were designed in the 1950s and we've been using the same ventilators since then. The advantage over the iron lung is, first, it's very much lighter. Second, it has a lid that lifts on a hinge at the ends so you can get into it without having to slide in and it's much easier. People who have good hand and arm function can get in independently and pull the lid down on top of themselves.

We have large separate motors that drive the units, which are a problem. The motors are large and heavy and run on AC 240 volts. They weigh much less than 800 pounds, and two people can move one easily. They're simple in design, very robust, and I'm sure can be manufactured for less than \$1,500.

Some people prefer to be in a chronic care unit rather than at home. In Australia we have no attendant system, so if you go home you are dependent on spouse or parents. I don't know the cost of home care of this type with support of a unit and a spouse or parents and disabled person, but I wouldn't be surprised if we found that it was cost-

effective for some of these people to be in hospitals. If the individual wants to be there and it's cost-effective, I think it's clearly the best decision. The vast majority of our long-term patients do leave the hospital at least for short periods, sometimes only for 1 or 2 days, sometimes for a week, and sometimes for 6 months or more. Some only come back when they're ill.

Patients who stay at home depend on us for medical advice when they become unwell, for example, when they get a chest infection, they become increasingly tired and they don't know why, and when they develop new symptoms. Many use their local practitioner for advice on minor things, but call for advice on other problems. There is a fear that the local physician will not know what to do with their disability. The local physician sometimes doesn't know what to do even though it's something very trivial. So first, they depend on us for medical assistance.

Second, they depend on us for technical assistance. We have one full-time technician, not four, unfortunately. He is responsible for the maintenance of all the ventilators in the hospital, plus all the ventilators in Victoria. He may have to travel quite long distances, several hundred miles, to repair a ventilator, repair a motor, install a new ventilator, or relocate one.

We have an excellent physiotherapy unit. These physiotherapists will visit at home, although they usually ask the patient to see them in the physiotherapy department if there is transportation available.

We have good social workers. Our patients depend on them for advice, particularly regarding financial problems in, for example, equipment purchase. We provide transportation if the patient is unable to drive or find a ride. We are available for consultation by telephone at all times, and often we can solve things over the telephone, which saves the person the trip to see us.

In Australia there are no agents for the latest in respiratory equipment. We have been totally unable to get adequate details about much of this.

One of our biggest problems is with the internal administration of our own hospital and attitudes about our unit. We have two people on our team: the medical director (me), and the secretary/business manager/respiratory therapist/physiotherapist/social worker; the sister in charge. We do also have a social worker and physiotherapist but she does both those things. For the unit to actually work, these people have to be flexible, innovative, and imaginative. In fact, this does not fit the traditional running of the hospital and upsets the management and the administration. We have noticed continual resentment and fear of the place, because it goes against their grain for us to be dealing with

people like this. We deal with them as people rather than patients and I think it's to their eternal credit that they don't bow to these pressures.

We have a very ad hoc arrangement in Australia. It's poorly funded, and it's given low priority by both government and hospital administration. But it does work and works only because of the good will and inventiveness of the participants — both the people who need the help and the staff.

### **Home Ventilation Program at Children's Memorial Hospital**

Eveline A.M. Faure

The home ventilation program at Children's Memorial Hospital was started in 1979 when more and more children had survived catastrophic illnesses and were remaining in the acute intensive care unit because they needed a ventilator to survive. The patient's medical condition must be stable. This means there should be no need for diagnostic or therapeutic intervention for 1 month. Also, the patient must be optimally ventilated on his ventilator, so that all his blood values, oxygen and carbon dioxide are normal.

The family situation must be appropriate. The family must accept the responsibility and training in home care, must have certification in cardiopulmonary resuscitation, training in respiratory and nursing care, and be able to perform this care. Also, the patient's family must have an adequately adapted home.

Third party payers must be willing to pay in full for the home care. Reimbursement must be guaranteed for all required equipment, which means two mechanical aids for breathing, monitors, and disposable supplies. Reimbursement must also be guaranteed for total nursing and respiratory care. This means 24 hours a day, 7 days a week, for the first month with the option to continue total nursing if needed. This was done to prevent family burnout and rehospitalization of the child, which is costly.

The organizational prerequisite was for a primary team, which consists of the primary physician, the nurse, the respiratory therapist, the social worker, the hospital administrator (if needed), the family, and other institutional or community representatives.

Team meetings for home care planning are organized to discuss objectives, write out action plans, and see that they are fulfilled. Nurses and parents are trained and certified in home care in the hospital. Equipment lists are made out, and the equipment is ordered and tested in the hospital before the child goes home. Home adaptation must be provided and completed before discharge. Community services such as the fire department, ambulance, school district and other needed services are identified, notified, and must accept the

responsibility. For the initial transition at home, the respiratory therapist and a nurse for home care from the team remain in the home for the first 24 hours to help the family with the newest task at home.

Eighteen children from 1 to 12 years old with various and complicated diagnoses, such as muscle weakness, spinal cord injury, neuromuscular weakness, or nonfunctioning spontaneous respiratory drive, and other pulmonary diseases, are now living at home in Illinois. This was done with case by case management. They go to school now, either in the community in the normal high school or under private tutoring at home. Their health is improved. They have very few infections, their growth is continuing, and they are united with their families and friends.

In all of these cases, there was an immediate cost reduction by 70% to 75%. Instead of \$1,000 for a day, it now costs \$250 or less. A study done by the State of Illinois has shown that there are over 100 more children presently in hospitals in Illinois who could go home on a safe home discharge program.

There are problems, too. The families still face financial reimbursement problems. If the child is receiving Medicaid and the father is working, the family has to pay a portion to Illinois, a portion that sometimes can be more than \$1,000 a month,

which puts a large burden on the family. Often a family of four is only allowed to have \$360 per month income, which is not much to live on. If the full reimbursement is provided, there are still delays in payment. Sometimes the nurses are not paid for 6 to 8 weeks because of this problem. The Surgeon General called a workshop to deal especially with the problems in funding and reimbursement last December, and insurance companies and presidents of third party paying companies attended to become aware of the problems that existed.

At this conference solutions were proposed, one of which was the formation of the Illinois Network for Home Care for Children with Disabilities. This network comprises the State of Illinois Department of Crippled Children, the University of Illinois, Northwestern University, the University of Chicago, and anybody else who wants to participate. A detailed program is now being designed to help children in the transfer from the acute care unit to the home or a home-like environment. Everybody at the conference concluded that home care for the ventilator-dependent child improves health. This shows by the decreased numbers of infections, the family health, and the social interactions with friends. In addition, the cost of health care is always decreased by at least 70%.

# POST-POLIO ACTION PLANS

## SUMMARY

Following Jack Genskow's summary of the polio-related sessions of the conference and a report of the Action Committee chaired by Father Lewis, the conference participants concluded that:

- Polio is still endemic and epidemic in many parts of the world.
- Insufficient research is being conducted regarding the many unanswered questions about the long-term effects of polio on polio survivors.
- Available knowledge on current health problems of polio survivors is not sufficiently disseminated among health care professionals.

To develop action plans, the participants voted unanimously to empower Gini Laurie to appoint a Steering Committee of 15 members and to charge the Committee with developing action plans for:

- Urging the World Health Organization, governments, and agencies to promote immunization programs against polio.
- Insisting to governments in countries where polio has been controlled that travellers to non-polio-controlled countries be immunized.

- Urging the United States government to enforce its polio immunization policy.
- Making governmental representatives aware of polio and post-polio problems via the Conference proceedings and hearings on research, information, training, and funding or programs to address these problems.
- Clarifying the current policy of the March of Dimes toward polio survivors.
- Forming local support groups through independent living centers, local chapters of organizations such as the National Easter Seal Society, and rehabilitation centers.
- Forming alliances with other respiratory and chronic disability populations.
- Enlisting the support of Disabled Peoples International, Rehabilitation International, and similar organizations.

The above resolutions are a general charge to the Steering Committee. The Committee will report back to a Third International Post-Polio Conference to be held in 1985 or 1986.

### Summary of Ideas Generated at Conference

Jack Genskow

My role is to try to summarize the conference.

- Polio is the most common, and the worse disease in the world today.
- The Easter Seal Society has provided some help for polio survivors. John Garrison, Executive Director of Easter Seals, says, "The effects of aging on these persons as well as new technologies for helping them to manage their disabilities are two areas that hold special interest for Easter Seals at this time. We look forward to learning more about these trends."
- We want to request from the National Foundation for the March of Dimes a policy statement. What are they going to do with us, the polio survivors? What is their policy towards polio? Once they become public about these issues, maybe we can react.
- Questionnaires from Warm Springs, from Manitoba, from TIRR, and from Goldwater have been sent, and I think we need to know what the results of these are.
- A major problem discussed was that physicians don't know about polio survivors.
- To communicate some of our problems, a handbook is being prepared to deal with the history of polio epidemics, Salk and Sabin vaccines, the fate of the survivors of polio, the estimated numbers

that are disabled, the needs of polio survivors, and an emphasis on the fact that their medical needs do not differ significantly from those of other individuals if the problems to which they are predisposed are recognized.

- We also need to communicate the need for immunization. Perhaps we need another Roosevelt or another English soccer player to dramatize the needs. From some descriptions of polio survivors, they are outstanding people. In Manitoba a follow-up study of respiratory and non-respiratory survivors found them to differ in some ways.
- The current problem, post-polio syndrome or post-polio muscular atrophy, we are still somewhat uncertain as to cause. There is ongoing research. Is it genetic? Is there a natural disposition? Is it part of aging? Is it a reactivation of the old polio?
- There is a need for periodic reassessment.
- We need a network of polio survivors.
- Wellness is an attitude with which you take control of your own life and make yourself well, and keep yourself well.
- We've also discussed frog breathing, and new equipment — plastic wraps, positive pressure uses, the pneumobelt, portable mouthpieces and battery chargers.

**Polio Survivors Association** Richard Daggett

Our association is "coping through communication." We started in 1974 with a loose network of alumni from Rancho Los Amigos Hospital in California. We started lobbying and demonstrating with the local government. We took several wheelchair ventilator-dependent people to the Board of Supervisors and showed the Board that these were people out of the neighborhood. Many were living on money from different federal and state programs, mostly funded through Title 19 or 20 of the Social Security Act, but the funds available for their care at home were not really sufficient. We convinced the Board that if even three or four of us went back into institutions, the cost would be astronomical. Therefore it made good fiscal sense to them to grant supplemental income to those people with medical needs.

Also, we lobbied for a transportation system with a vehicle equipped to handle ventilator equipment. In southern California there are many communities with Dial-A-Ride Services or Para Transit, usually confined to their own city limits and most not able to haul reclining wheelchairs. Today there is one vehicle, only one, but it goes all over the county, about 200 miles a month.

**Polio Information Center** Harriet Bell

Two years ago, at the First International Post-Polio Conference, I gave you a preliminary report on the original "Post-Polio Questionnaire." Here are some facts based on the first 700 questionnaires:

- People between the ages of 11 and 85 have replied.
- There have been replies from all but 7 states, plus China, Puerto Rico, Australia, England, and Canada.
- Women accounted for 464, or 66%, of the respondents; the average age was 50.2 years.
- When people reported their physical changes,

we found the following:

- 17% indicated depression
- 10% reported dizziness
- 18% reported interrupted sleep
- 15% reported gastrointestinal problems
- 15% indicated they had returned to respiratory aids
- 25% reported fatigue

The intent of this study was to determine the needs of polio survivors across the country. Other issues, the social/psychological factors kept appearing, particularly the quality of life.

The Polio Information Center, a referral center, is the beginning of a permanent file of polio survivors across the country. The center will continue the questionnaire and the newsletter, evaluate and publish the findings of the post-polio questionnaire, make available polio-related materials, and establish the need for a hotline.

**Easter Seal Societies** Rita McGaughey

We have a network of Easter Seals across this country in every state and in Puerto Rico and Hawaii, and we are not at all disease related. Anyone with any physical handicap can receive services from the Easter Seal Societies, and we do encourage you to maintain close contact with the Easter Seal Societies in your communities.

We are interested in research on how the aging process affects some of the disabilities caused by polio, among other disorders, and we also are interested in research into the skills and technology needed to manage disabilities.

Our research foundation was founded over 30 years ago, and until this week we have looked at the causes of disabling conditions. Now we will formally change and look at the management of disabling conditions. The data your organization and some of the other groups that you represent have gathered can be interesting for all of us.

# ESSENTIALS OF LIVING INDEPENDENTLY

## SUMMARY

Ed Roberts, one of the founders of the first Center for Independent Living in Berkeley, called his assistants, "the key to my life." He explained, "I have always had multiple assistants... several people coming in and out of my life... If you are going to be strong and free and independent you need to make the choice as to the kind of person you want to live with you or to work for you."

California began an attendant care program in 1958. This year the maximum benefits for a severely disabled person are around \$900 a month. The total cost of the program is around \$225 million — probably the largest of its kind in the world.

"Unpaid assistants," said Jack Genskow, "are people who care for disabled persons for relationship reasons — family ties, friendship, love, marital commitments... There are several components of burnout — low energy, chronic fatigue, emotional exhaustion, depression, helplessness, and even entrapment... It is insidious, it creeps up on you... It is a general erosion of the spirit... Burnout occurs when one person does all the receiving without recognition of the needs of the person giving." He suggested several strategies to prevent burnout: keep communications open, develop an effective social support system, share what you're really feeling, rotate duties, and get away when the situation is stressful.

Peg Leonard, a longtime *Gazette* friend, died just before she was to have attended the conference. Her paper had been taped by a friend because Peg had been having problems with her voice. "Having been hospitalized," said Peg, "for three years, I appreciate the superiority of good home care as com-

pared to a communal setup... The privilege of being the sole patient means one has certain responsibilities to exercise extreme thoughtfulness."

Adolf Ratzka of Sweden contrasted the usual agency-run system, which has a tendency to over-protect and limitation of initiative, to the disabled-directed system which he and a few others use. "To the disabled individual," he said, "the way attendant services are organized is at least as important as the number of hours of assistance... If somebody is to be trained, it should be the disabled person. Motivating and directing another person take some psychological and educational skills, which have to be learned."

Gill Whitworth described the unique attendant care system Dr. Spencer organized for a few ventilator-dependent polio survivors through a London hospital. "It is extremely important," she stated, "to maintain your privacy... A lot of us are putting up with a lot of things. It is a question of how much quality of life you expect and demand."

Jan McMurphy, who has been working as an attendant for six years, defined an attendant's work. "Do anything," she said, "that makes it possible for your employer to live independently in the home... The most important things about being an attendant are joy, pride, and maintaining a sense of humor... To be an attendant you just have to be an extremely responsible person and have a professional regard for confidentiality... My employers have trained me... I am an extension of the employer's body and that's why it is such a close relationship."

## PERSONAL ASSISTANTS — PAID AND UNPAID

**Attendant Care Programs** Edward V. Roberts

In California around 1958, an attendant care program began. This year the total for that program in our state is around \$225 million; it is probably the largest program of its kind in the world. New York also has a program, and Massachusetts has a very small program.

The best advocates we have in California are people who have been attendants and who know disability intimately and are now working with us in the political arena. We started the first attendant pool in Berkeley. One of our biggest problems was how to find the kind of people we needed to live independently. My mother worked with the disabled student program at Berkeley, and she started the

first attendant pool. We found that the word spread quickly that there were part-time jobs for which you could be paid. There were jobs for women who had children going to school, for students who were not going to school, and for ex-drug addicts; just about every kind of person you could think of would come in and apply. We screened hundreds of people, and the program became a prototype for the California State Program, and now the California State Program has become a prototype for countries like Australia, where disabled people are struggling for the same opportunity to be independent and to live a life of choice rather than a life of dependency on institutions.

My path to freedom was through education, and

all through education I had multiple attendants; I never really had just one person. I felt it was important to have several people who would enter my life when I needed them. Some would stay and live with me, but mainly people came in and worked in the morning, got me up and going and then left me alone, to go to work or whatever I was doing. They would come back in the evening. I've had up to nine attendants at one time.

We just finished a new movie called *The Attendants*. It is a half-hour documentary that I hope will be ready in 3 or 4 months. We think it will be a national television special as we expand it. It is the first documentary I'd ever seen that really describes what happens in the relationships.

If you can't make a choice about the kind of person you want to live with you or to work for you, you're in real trouble. It is these choices, the choices in housing and transportation and personal assistants, that can help make us strong and free and independent.

Where there are personal assistant programs and where you have the freedom of choice, you'll find an active group of disabled people. That's one of the reasons California is so much in the forefront, because we've had that attendant care program since 1958. This year the maximum benefits are nearly \$900 a month, and with that you can take care of yourself.

#### **Unpaid Assistants and Burnout** Jack Genskow

Burnout is low energy, chronic fatigue, weakness and weariness, general complaints, emotional exhaustion, and other feelings of depression, helplessness, copelessness, and even entrapment. It includes mental exhaustion and the development of negative attitudes toward yourself, feeling badly about who you are, feeling badly toward yourself and others, toward work and about the whole life situation in general.

Burnout is insidious; it creeps up, sneaks up on you. It is a general erosion of the spirit. Burnout occurs when one person who gives much does not have personal needs met adequately. One person does all the giving, and the other person does all the receiving without any recognition of the needs of the person giving.

When you become aware of the burnout problem, take responsibility for doing something about it. The relationship is basic to this, and the important thing is to try to keep that relationship alive. That is usually the key motivator, the responsibility of both people involved. Since the personal care attendant gives so much more than is physically observable, the disabled person has the responsibility of being aware of his or her attendant's needs and trying to meet them.

How do you fight burnout? Here are several

ways. Develop an effective social support system. Try to find a support group. This allows receiving feedback and rewards, raising concerns about conditions, and having discussions about feelings and reactions. The sharing is personal and genuine, not just conversation, but self-disclosure, sharing what you're really feeling.

Periodically distance yourself from the situation at crucial times. You need time away when the situation is stressful. Get away: it is a safety valve.

Develop individual strategies, define your own best way to meet with stress, know what it is, and use it.

#### **Unpaid Assistants and Developing**

##### **Self-reliance**

Peg Leonard Layton

Let us remember always to exercise extreme thoughtfulness when it comes to those persons who care for our daily needs. Often people who show considerable interest in the disabled are classified as unpaid assistants, and serve without thought of financial retribution. It is easy to become so accustomed to the excellent services these dear people provide for us that we request favors which keep these helpers constantly on their feet, running hither and yon. I would like to offer some suggestions to develop self-reliance:

- Find underdeveloped resources.
- Focus on the solution, not the problem.
- Use your imagination.

#### **Swedish Attendant Care System** Adolf Ratzka

Do you want to have attendants, or whatever you call those people who are sent to you by some agency, or do you want to have the freedom to choose for yourself? To the consumer, the way attendant services are organized is at least as important as the number of hours of assistance.

In Sweden there are personal assistant programs for the physically disabled at home, at school, and at work. They are administered by different public agencies. Attendant care at home is under the responsibility of the local social services office, and the staff there are charged with case finding, visiting consumers in the home. About 4.5% of the total Swedish population use these services. Needless to say, over 90% of the consumers are senior citizens, although the same social workers and assistants work with both elderly and young consumers.

In Stockholm a single person with an above-average income whose assistant works 40 hours a week pays the equivalent of about \$30 a month, which is the highest fee. This amount corresponds to about 2.5% of the program's cost to the city. The state government pays 35%; the rest of the cost is financed by local taxes.

From 80% to 90% of the assistants are female, often middle-aged housewives. Assistants are com-

monly referred to as Home Samaritans, and their pay is, accordingly, the lowest municipal wage. Consider for a moment what the term *Samaritan* implies in terms of the consumer's role. Assistants are organized in small teams who work for a certain group of consumers. They meet every morning in an office in the neighborhood and plan the tasks of the day. Some conflicts between consumer and agency result from this particular organization. The system makes a very clear distinction between subjects and objects. The subjects are the professionals, and the disabled are the objects. Since the system is run by professionals, improvement is seen mainly in terms of more than higher forms of professionalization. All parties involved, including the organizations of the disabled, push more education for the assistants.

Given the diversity of our needs and habits, the usefulness of such training to me seems limited, although some attendant care consumers contend that the less health care-related training attendants have, the easier it is for the consumer-directors or attendants. If somebody is to be trained, it should be the disabled person. Motivating and directing another person take some psychologic and educational skills, which have to be learned. Besides, the turnover rate among attendants is much higher than among consumers, which makes an investment in his training more meaningful.

The structure of the service leads to another problem. Since I'm disabled, my home is also a place of work for several persons, who have the right to good working conditions. What constitutes good working conditions is defined by the National Association of Local Governments in negotiations with the Swedish Union of Local Government Employees. It is common that a representative from the local services office visits a consumer's home to determine whether it conforms to Union requirements, and these Union requirements are extensive — the bed has to have a certain height, and so on. The organization of the Swedish Attendant Care System also has a spatial dimension with implications for the consumer's geographic and social mobility. Administrative and financial responsibility rests with local governments.

Because of differences in the tax base and social priorities, there are large regional variations in personal assistant services in Sweden. Two-thirds of our communities provide no service after office hours and on weekends. Severely disabled persons then have to rely on relatives, pay for private help out of their own pockets, or move to an institution. As a result, if you live in a community with a decent service, you dare not move. Relatively few severely disabled people live by themselves because the cities cannot provide individual attendants at odd hours or for extended periods. In the larger cities

these people tend to live in arrangements that abroad are commonly called Fokus apartments. In Stockholm they are now usually referred to as service apartments or concentrations. Briefly, a Fokus concentration consists of 6 to 15 specially designed apartments interspersed through an apartment complex of 100 or 200 regular apartments. From a staff room on the premises, attendants are on call 24 hours a day, but as the term *concentration* implies, Fokus apartments are based on geographic clustering in a limited number of locations. The Fokus situation has received favorable attention outside of Sweden, but is incompatible in the long run with the goal of mainstreaming the disabled.

This brings up an important point. If the disabled are to fully participate in society, they have to have the same degree of freedom in the housing market as the rest of the population. Attendant services follow the consumer, not the other way around.

The agency attendant care service, such as the Swedish one, has an inherent tendency toward professionalization and to the dangers of overprotection, social control, and limitation of the individual's initiative. This is precisely the opposite of help for self-help. In my opinion, a personal assistant service that encourages and awards independence must be run by the consumers themselves. In Sweden our first step in this direction seems possible within the present system. Several severely disabled persons are living by themselves in Stockholm. The social workers could not arrange suitable attendants at the times they were needed, so these consumers took the initiative and now recruit, train, and schedule their own assistants, although assistants are formally employed and paid by the social service office as before. These consumers have as many as 10 assistants each, and they are scheduled to work certain hours a week. They function as backups. By having so many attendants with an average of about 5 hours a day, a consumer can achieve a flexibility approaching that of a 24-hour service.

The reason why more people do not have such a service is probably that they expect the social service office to provide the service and are not aware of the possibility of doing it themselves or aware that they live in one of the city's concentrations. The necessary ingredients to your own system are proximity to sufficiently large potential labor pool and some administrative skills. This gives consumers better service. You also must be your own personnel manager, providing an excellent opportunity for acquiring important social skills and assertiveness.

In Stockholm I estimate that up to 40% of the total cost of the service could be saved this way. In the long run a further step is necessary in Sweden:



as I pointed out earlier, the extent and quality of personal assistants are local government options. For a severely disabled person to choose a place of residence, personal assistants have to be financed by a tax-funded national rather than local attendant care insurance. By way of summary I have described an agency-run personal assistant system and its implications for the consumer. I contrasted such a system with a consumer-run service. The two models are not mutually exclusive. They can be seen as the extreme points along a continuum. Also, a whole range of intermediate solutions seems possible, where the various tasks of administering an attendant care system, such as recruiting and training, are allocated differently between consumer and agency. As an individual acquires more skill and confidence, he or she can gradually take over more functions, with more independence and pride.

**An Attendant's Point of View** Jan McMurphy

Being an attendant is a matter of personal style. The definition of an attendant's work is: just do anything that makes it possible for the employer to live independently in the home. The most important thing about being an attendant is maintaining your sense of humor. To be an attendant you have to be an extremely responsible person. An attendant is an extension of the employer's body and that's why you're so close. Doctors and nurses don't under-

stand that an attendant is a professional. I find that the attitude of the public at large toward an attendant is that you're lower than scum.

**English System for Assistants** Gill Whitworth

I will briefly describe what disabled people in England receive. We have a state system which theoretically looks after everybody, but if you go into hospital you don't pay, then when you go home you're lucky if you have a district nurse for an hour a day or so. You have home helpers who are supposed to come and help with your daily living activities, but most disabled people have a pretty tough time.

I personally like the idea of having people for a short time because they've got their own interests. You can help them to develop their interests if you like. Usually attendants are not going to take over for you because they're young and they're doing their thing.

Obviously there is a reciprocal relationship, but I like the idea of short-term attendants because they remain spontaneous. You don't get bored with them. After all, looking after a disabled person is a bit of a dead-end job: you don't exactly have career prospects. If you are doing this for a short time, I think you can handle it better, and if you are doing it because it is helping you toward something else, that is good, too.

# MECHANICAL ASSISTANCE HIGH AND LOW TECHNOLOGY

## SUMMARY

"The problem," claimed Theodor Dukes, "is not what kind of additional technology we need but how can we make the technology available... My arbitrary definition of low technology is that it is below \$1,000; above that amount it is high technology... In the future, microprocessor technology could make maintenance of ventilators much less expensive... The computer is of utmost significance to the disabled in the areas of education, communication, and work opportunities."

John Dalhaus described the microfilm viewer which he has developed for his quadriplegic brother-in-law.

Bob Gorski shared a list of the computerized data banks currently available. He discussed two organizations of the disabled which specialize in comput-

ers — CAPH-2 and Handicapped Source — and the advantages of working at home. Working at home is less stressful but it cuts down on interaction with other people; there may be additional tax write-offs but insurance will be higher.

Dr. Oldroyd described the small tabletop robot he has been using in his work at Washington University. "My interests are primarily in the computer-to-robot connection," he said, "and how to make robots work... The technology is available and all the components are present, it is a matter of putting the components together and getting enough people producing the kind of software needed to tie them all together at inexpensive prices so that disabled people can use them productively in simple kitchen and bathroom chores."

### Perspectives on Available Technology

Theodor Dukes

I'd like to define a few terms in discussing how to make present technology available. Another way of describing technology is as a reflection of or in relationship with the price. Below \$1,000, it is low technology; above \$1000, it is high technology. Do you need really highly skilled people to produce a product, or is low technology sufficient, where an item can be produced by someone without excessive skills. The high technology product in the future may very well be converted into a low technology product simply by making kits and drawings available for production at less cost.

To emphasize the low technology options, you have to have a design; you have to have drawings, possibly kits that can be distributed; you must have a frugal budget and quality control; and the information about the availability must be distributed. The best possible way for getting this going is through the organization that has existed for a long time, the Rehabilitation Engineering Society of North America (RESNA).

Top priority should be the use of microprocessor chip technology, applying it to existing high technology items, particularly those which have to do with life support, to improve their reliability. You could then have a readout or even communicate by telephone with experts about what is going on and possibly prevent a lot of maintenance and make needed maintenance much less expensive.

The potential problem here is economy. The initial device is more expensive, perhaps 10% to 20%

more, but not in the long run. The question is, can you get that scope into the system? We are talking about lifetime costs, and not just initial purchasing costs.

The other problem is that there are many excellent service organizations that provide these devices, but it may not be in their interest to have less maintenance. We have to strive for some very fundamental changes in attitudes and make it economically attractive that less maintenance is better.

The other item in terms of microprocessor technology is the computer.

### The Microfilm Viewer

John Dalhaus

Electronics to aid the disabled involves the use of a microfilm viewer as a reading and reference device. This may not be as sensational as other electronic aids, but it can be a valuable tool to those who may not be able to get a book off the shelves or to turn pages.

I have modified the viewer for sip-and-puff operation, so I can add fast forward and fast rewind. For information, please write to National Micrographics Association, Services to the Handicapped Committee, 8719 Colesville Road, Silver Springs, Maryland 20910.

### Sources of Free Information and Home Employment with Computers

Robert Gorski

A program called the ABLEDATA System is housed on the east coast. You can access its information through a number of ways: through your own computer, if you happen to have one, through informa-

tion brokers, an example of which would be the Moss Rehabilitation Hospital in Philadelphia. There are a number of agencies like Moss that are providing services to disabled people, but they also act as information brokers, housings, or library sources for information. Moss has information on many things: travel, medicine, products, but they are just one of the many information brokers for the ABLEDATA system. The ABLEDATA System is a computerized data retrieval system for rehabilitation products. It is funded by the federal government by a grant.

Accent on Information is a commercial computerized product database with data entries organized by categories of equipment and by disability function. Entries include ideas for how to make or adapt equipment and organizations of interest to the disabled person. The total database includes 5,400 entries, representing approximately 1,000 companies, developers, and organizations.

The Automatic Retrieval of Information on Assistive Devices is a computerized product database with entries organized by disability and product function. The total number of entries is about 750 representing 25 companies. Information is provided free by either telephone or mail. Each data entry provides the manufacturer's or distributor's name and address, price, and a 100-word description of the product.

Then there are opportunities for working at home using your computer system as a means of employment. The use of computers in home employment has become so widespread that there is actually an organization of disabled people doing this. I was really excited about this and I recommend that you investigate this personally. The name of the organization is COPH-2 and it is located in Chicago at 2020 Irving Park Rd. They produce a newsletter called *Link and Go*. You can get that newsletter by calling 312-477-1813, and sending \$8.

We also now have the Handicapped Source out of Michigan. It is a booklet that describes, briefly, some of the adaptive computer equipment available on the market. By adaptive I mean that computers have been designed to be operated by people with hearing impairments, visual impairments, speech impairments, muscular impairments, and mobility impairments. Handicapped Source is a division of Intelligent Consumer Electronics at 526 Langfield, Northville, Michigan 48167.

## Robotics

L. Andrew Oldroyd

A number of applications have been investigated for the use of robots with handicapped people. There are five or six universities where there are projects exploring this. Most of them are working with fairly small robots, but these still cost in the

\$50,000 range. For this \$50,000 or \$80,000, you get a robot that you can teach to do things. It comes with a box connected to it by a cable, and you can push buttons to make the robot move to different points with different configurations, such as the hand open or closed on something, or the wrist pointed in different directions. When you've moved it into a position where you want it to do something, such as pick up a glass, you can move each joint independently until it is about to do what you want, pick up a glass. At that point you push another button so the robot memorizes this point. Then you move it more, causing the hand to actually close on the glass, and once again you push the button to tell it to memorize the action. You push the buttons for a while until the glass is turned the way you want it, and you make the robot memorize again. This is how it learns a new point. You keep teaching it until you've gone through a whole sequence, such as grabbing a glass, turning it over, filling it with water, picking it up again, taking it to your mouth, and tilting it so you get a drink. You may have to teach 100, 200, or 300 points to teach it to go through some relatively simple sequence.

Each one involves a lot of manipulating of the controls to get the robot positioned exactly right. Once the robot is taught the moves, though, all you have to do is push *replay*, and it will go back through that exact same sequence as many times as you want it whenever you want it. There is a drawback: the glass must be in the same place at the start every time, you have to be at the same place it is going to pour every time, and the glass has to be equally full every time, etc. In other words, everything has to be in the same place. If the glass is too full, it pours before you're ready; if you reach to get the glass at the wrong place, it just pours water on you; it doesn't care, it is not like a human helper.

This is what you get with robots. This is also what you would normally program yourself, given one of these home computers and a little robot attached to it. The technology is available and all the components are present. It is a matter of putting the components together and getting enough people producing the kind of software needed to tie them all together at inexpensive prices so that disabled people can use them productively in simple household tasks, freeing the disabled from having personal assistants who do everything. You can do your own kitchen or bathroom chores and wash your own teeth, with your own mechanical arm doing your bidding. You would have a level of independence not otherwise available.

# REWARDS OF LIVING INDEPENDENTLY

## SUMMARY

"Disabled parents must develop a strong fortitude in dealing with the public," stated Val Parrish. "The public is oftentimes shocked, awed, outraged, and baffled when they see a disabled couple raising a family . . . Children of disabled parents grasp early in life that there are many solutions to daily difficulties. This positive approach can only enhance their outlook on life . . . The important factor is the love that is felt and shared."

"The adoption of 15 children in our 25 years of marriage," said Grace Sandness, "has been a really exciting experience . . . When we started, nobody else was doing it . . . If you find an adoption worker who treats your disability as just another facet of your life-style and not as the dominant thing, then you have a good chance . . . In parenting, most of your problems are just extensions of so-called normal problems and the disability doesn't make any difference . . . If anyone wants help with adopting, just write to me."

The disabled father's role in raising an adopted daughter was discussed by Max Starkloff, "She has never responded to my disability in anything but a very natural way . . . The important thing is to compensate for those things you cannot do and to let the child get to know you very well." Colleen Starkloff suggested finding an agency to act as an umbrella, then developing a resumé and distributing it to physicians, social workers, and other people who might know of a child who will be adoptable.

"We had a wonderful social worker," said Jack Quigley, "who worked with us for several months on a home study . . . We were interested in the idea of an international family, so we sought our children from a foreign country . . . We found our lovely Sara in India through a friend of Nancy's. Our second adoption involved a trip to Honduras. We had to convince a social worker there that my physical

disability did not prevent my being a perfectly capable father."

Nancy Quigley discussed the emotions of adopting and the reactions of children to a disabled parent. She described the grief process involved in realizing that you were not going to bear your own children and compared adoption to a regular labor and delivery. "When the children come, you forget all the bad parts . . . You go through a bonding period . . . Then you feel you couldn't love the children any more if they were your own . . . Sara has done a good job of working through some anxiety about her father's disability. She makes her friends envious because he is in a wheelchair and has an elevator."

Marilyn Potter, who has worked in adoption in Ontario for 23 years, added, "Parenthood is a process of mutual nurture . . . Years after adoption, the children say that what really mattered was the parents' appreciation of them as they were as a person . . . and their relationship of caring and hope and expecting."

Yvonne Duffy discussed the difficulties of people who were disabled in finding out anything about sex. "My mother told me about the birds and bees at the usual time but told me not to bother because I wouldn't be able to do it anyway . . . That kind of false information can hurt us. We should make sure that present-day disabled children have a really good factual sex education program."

In his presentation on fertility for spinal cord injured persons, Dr. Halstead recommended research on the impairment of sperm production and on ways of optimizing the production of quality sperm. "We need," he stated, "to initiate and continue a discussion of the humanistic and ethical issues involved in manipulating nature in ways that impact on people's lives in very far-reaching and yet very personal ways."

### Disabled Parents Coping with Life

Valerie Brew Parrish

Love, marriage, and raising a family are aspects of life enjoyed by many physically disabled persons. Despite the public's misconceptions that disabled persons are asexual, a large percentage of the disabled population lead active lives as wives, husbands, mothers, and fathers. Universally the act of mating and reproducing is expected of its peoples. Inexplicably, the population is often shocked, awed, outraged, and baffled when they see a disabled couple raising a family. Limited exposure and

a lack of understanding of disabled persons can be attributed to the public's ignorance in dealing with this situation.

Disabled parents must develop a strong fortitude in dealing with the public. As if hypnotically drawn to a carnival freak show, some individuals have an insatiable curiosity and can become quite meddlesome when they see a disabled couple with their offspring. These individuals lose any semblance of etiquette and boldly approach the disabled couple with their onslaught of questions. They demand to know whether the child will be able to walk, talk,

see, or think. It is erroneously assumed, in many instances, that the offspring will have the same disability as the parents. Frequently the disabled parents overhear the coy, knowing whispers lamenting the tragic fate of the family. The humiliating, patronizing pats on the head from total strangers can be unendurable.

The public's ambivalent perceptions of disabled parents can alternate from one extreme to another. Some perceive the disabled as vile creatures who should be shunned, while others utter platitudes to describe the disabled couple as amazing and courageous. Disabled persons frequently fall prey to fanatical religious zealots. These zealots are only too eager to pounce on the disabled person in order to perform a miraculous healing. When the disability remains unaltered, the disabled person is dutifully labeled a sinner not having any faith, thereby rationalizing that the magic incantations and blessings only work for worthy believers.

Much to their chagrin, disabled parents who are subjected to this behavior are left with the problem of how to effectively handle these offensive remarks. A negative retort only reinforces the unjustified stigma that all disabled persons are bitter. A candid reply might serve to sensitize and educate these meddlesome individuals if the information is not misconstrued. Occasionally it may be ludicrous to dignify some remarks with an answer. Disabled parents can be made to feel like human extraterrestrials by the blunt stares, comments, and expressions of passersby.

Children are nonplussed when it comes to their parent's disabilities. Mommy may have to change diapers with her feet and Daddy may have to use his hands for eyes but the children readily accept these conditions as simple facts of life. The important factor is the love that is felt and shared between the parents and children. Nowhere is it dictated that parents are required to have all limbs and sensory organs in perfect working condition. Good parents take time with their children, listen attentively, and provide a loving, supportive home life. Biases and prejudices do not dwell in the hearts and souls of little children. They are able to evaluate situations realistically. In their eyes, Mommy and Daddy are not oddities; they are the people who provide love and safety.

Disabled parents often must be creative in adapting the environment to accommodate their needs and the needs of their children. If the parents use wheelchairs or have limited reaching ability, shelves and closets may need to be lowered for easier access. Single-lever water faucets may have to be installed for more convenient manipulation. Ramps and widened doorways may provide additional maneuverability for exiting and entering. Adaptive equipment may be needed for a myriad of

tasks. Hand controls or foot controls may be needed to drive a vehicle. Optacons or other reading devices for the blind may assist the visually impaired person to have access to printed materials. Disabled parents are usually accustomed to ways of identifying what needs to be done and then finding appropriate solutions. For example, a baby's crib may have to be lowered to facilitate smooth transfers when lifting the baby from the floor to the bed. Conventional cribs have side rails that lift up and down. It is often more advantageous to hinge the sides of the crib so that it swings out like a gate; this modification will permit the disabled parent more room and flexibility in handling the infant. Bells may be tied to the toddler's shoes to give the blind parent an auditory cue as to which direction the baby is headed. Special care and consideration may be given to the selection of appropriate clothing for the baby. Clothing that contains too many buttons or snaps can be avoided.

Children easily adapt to the needs of their parents. If a parent is unable to lift the child, it doesn't take long for the infant to understand this fact and soon learn to crawl up on the parent's lap. If a parent is blind, the child quickly learns to describe things in detail and rapidly jumps out of the pathway of the blind mother or father. As children grow older their physical needs become less demanding. Children of disabled parents grasp early in life that there are many solutions to daily difficulties. This positive approach to daily inconveniences can only enhance their outlook on life. Parents are role models. They unconsciously teach their children coping strategies. Perhaps disabled parents prepare their children to empathize more and to deal with adversities more effectively.

Both disabled and the nondisabled population basically want the same things in life. All humans need to feel loved. Marriage and raising a family can be the most rewarding part of life. Love, marriage, and bearing children should not be off-limits to the disabled. A physical impairment need not preclude having a family. The majority of persons with disabilities do not have disabling conditions that are transferable genetically. Disabled individuals are people, not helpless victims, as so commonly described. Likewise, the disabled are not afflicted. Terms such as *victim* and *afflicted* convey images of weak, sickly, helpless individuals who will eventually wither away. These terms are only used to evoke pity. Disabled persons come from every walk of life, and anyone can become disabled. Disabled individuals hold professional jobs, buy homes, and pay bills and taxes.

Life would be less complex if adults could see reality as children do. Blessed are the little ones for they can accept people the way they are. They don't see the disabilities — they see the person.

## **Adoption**

Grace Sandness

We adopted our first child through Holt Adoption Program. The first two children we took were handicapped, and most of our kids have some sort of problem. I'm not advocating that for everybody. We got Cindy, who was 5 and had cerebral palsy, and Jenny, who was 4 and had had polio, when my husband was working as an intern rehabilitation psychologist, finishing up his PhD. He felt we could do something for these kids that a so-called normal couple couldn't. That was the basis for choosing kids like that.

Adoption of 15 children has been a really exciting experience and it seemed as though while we were doing it, especially in our early days, nobody else was doing it. As an adoption counselor, I've worked with 5 couples who have had one disabled partner, and it has been working out great. It is getting easier and people are being much more open to it now. If you are single, you're going to have a hard time simply convincing agencies to let you do it, but there are ways around most things. If you find a counselor or adoption worker who is able to treat your disability as just another facet of your whole life-style and not as the dominant thing, then you've got a good chance. If anybody wants information, lists of sources or such, just write me at 9965 Quaker Lane, Maple Grove, Minnesota 55369. I think there are a lot of problems you can have in parenting, where the disability doesn't really make the difference. Most of your problems are just extensions of so-called normal problems.

## **A Father with a Disability**

Max Starkloff

I work with Meaghan as a father with a disability, a physical disability that prohibits me from doing certain physical things for her. It becomes difficult for me when she needs to be held, she's crying and she needs some tenderness, and I'm not able to pick her up and hold her. She obviously doesn't want to crawl up on my lap because she really wants attention, so I have to figure out the best way to compensate. I have found that spending a great deal of time with her in those more leisure moments has really helped me and, I think, helped her understand how to get along with me. We spend a lot of time walking and she is constantly talking, constantly asking questions. I find the two of us alone get to know each other a lot better. Now when she wants to take a walk or to go to the store, she asks me instead of her mother.

We also spend a lot of time reading. If I'm working at my desk at home I always let her crawl up on my lap and she'll mess up the newspaper or do something, but it still gives us the opportunity to share something and again compensates for those times when I can't do it. Also putting her to bed is interesting. When her mother puts her to bed, she

fights constantly about changing to her pajamas, and her mother has to put the pajamas on and do everything else. When I do it, Meaghan does it all herself; she realizes the difference, but she has never responded to the disability in anything but a very natural way.

I have many very close friends who are disabled, so it is not just me she is around. It is a very natural thing for her and she knows I don't walk and she talks about the fact that I don't walk and other fathers do but it doesn't make any difference. I think that disability is so natural that it will be very interesting to see what happens when she enters school and when kids start to ask her specific questions about why her father doesn't walk. I think as she grows up, because we are very natural about the disability, there will be nothing seriously negative about the disability that she sees.

## **Comment**

Colleen Starkloff

We have a list of people who may possibly be in positions to find out about children who are adoptable: physicians, public health clinic social workers, lawyers, people in all types of communities and in various types of work where they just might happen to know.

## **The Adoption Process**

Jack Quigley

When we first thought we might like to adopt, we went to our local family and children services and began the interviewing process, which was a preliminary to the necessary home study. I think we were a little bit concerned that we might be turned down because of my disability, and that apprehensiveness may have communicated to our social worker because in the course of that process, the social worker decided that we were not yet ready to be parents. The decision was based on the fact that I was at that time in graduate school and we had no steady income on my side, and Nancy was needed for the family income. We thought this was a very valid reason, but we also felt that we found in her tone of voice a fair amount of apprehension about my disability.

We waited a year or two, and as I began to earn a full-time income and Nancy was free to be a full-time mother, we applied again and had no trouble at all. We had a wonderful social worker who worked with us for several months on a home study and helped us through the various early decisions we had to make.

The first decision we had to make was if we wanted to make an American adoption or an international adoption. At that time we were told that we might have to wait 3 to 5 years for a healthy American infant for adoption. We decided that we had waited long enough at that point, and we were not interested in waiting 3 to 5 years more. Besides,

we were quite interested in the idea of an international family. So we decided to seek a child from a foreign country.

The second choice we had to make was whether to use an international adoption agency or to use private channels to find a child. We decided to use an international agency, so we applied through World Family Adoption because they were involved in a number of different countries. We also reviewed the possibility with Holt.

Then we filed our application and waited. Our social worker told us that we would get apprehensive and that we should plan to wait while the wheels turned. We indeed did get apprehensive, and we wanted the thing to move along a lot faster than it was. Nancy decided to write a letter to some friends of hers, distant acquaintances, who were then in India. As the letter was going across the ocean we got word from World Family Adoption that we had been summarily rejected by the Philippine government because of my disability, and furthermore there were no healthy infant girls in all of India, which was our second country, for adoption.

We waited for a week in utter despair, and a letter returned from India saying that several weeks before, Nancy's friends were at dinner with a doctor who spoke of a 2-month old healthy infant girl who was in a hospital in a little town nearby. She had nowhere to go, and he didn't know what to do with her, so our friends had taken her in but needed to find a permanent place for her. She is now our lovely Sara, who is 5½ years old.

Our second adoption involved a trip to Honduras, and while we were there we were not only dealing with another social worker who had to be convinced about physical disability, but I found myself in the position of having to assert myself rather heavily to convince that person that I was a perfectly capable father. I think you have to go into those kinds of situations not expecting equal treatment, but expecting to have to put out two or three times the effort to sell yourselves as parents that other adoptive parents might have to do.

### **The Emotions of Adopting and the Children's Side**

Nancy Quigley

When I realized that we were not going to bear our own children, I had to work through a kind of grief process. You have to grieve to give up the concept that you were going to bear your own children. A social worker was very helpful to identify for me the grieving you need to do. I think there is even a sense of failure when you realize you can't have your own children. All that had to be worked through, and I think we did a fairly good job of it.

The adoptive process is like a regular labor and delivery — it seems endless as it is going on, espe-

cially when you are doing a foreign adoption. The hurdles and frustrations and unpredictability of it all — sometimes even the pain — are like labor. There's a bit of injustice in it all when you're adopting, whether you are disabled or not, because you have to be evaluated, assessed, and questioned. They look at your bank account, they take your fingerprints, they look into your police record and all to see whether you're fit to be parents, and we all know there are people out there who are less disabled than any of us, but they are having children all too easily.

So it seems unjust at the time, but once the children come, you really do forget all the bad parts. In fact, it seems like a positive experience. I'm sure there are easier and more pleasant ways to get to motherhood, but I don't think we could have done any better if we had done it ourselves.

Our two children are very special, as all children are to their parents. People tell you before you adopt that once the children are yours they couldn't belong to you any more if you had had them yourself, and you don't quite believe it. It is true. When you adopt, you go through a bonding period. I don't think the minute they are placed in your arms you fall in love. It takes a while, just as with biological children. But once you reach the stage where you do belong to each other, you feel like you couldn't be closer or love the children any more if they were your own. I want to mention two factors that we've talked about, especially as Sara has been growing.

There is some anxiety occasionally in Sara that she has to work through about Jack's disability. I think children tend to have global anxieties and they're not able to understand. It is helpful for us as parents to be able to talk about their worries. Sara has been worried that she will be like Jack when she is Jack's age: In a wheelchair. This of course is irrational, but we have had to talk through this with her. I think this is probably a fairly common anxiety as the children grow.

Also, I think children, especially young children, tend to put themselves at the center of everything. There are times when they must wonder whether they are responsible for the disability. Again, this is terribly irrational, but you must reassure them that they are in no way responsible for the pain and the distress of the disability.

Those are our two anxieties. Also, I think we've been more aware, and I guess Meaghan hasn't got to this point yet, but I think Sara has been aware of the difference of her father. Children all have such a great need to be like other children, just as we all have a need to be like everybody else, to be like our peers. To have a father who is different has been something that she has had to work through. I guess I saw it a few times when she seemed a little

hesitant to invite friends home when Jack was going to be there. I think she has worked it through because now I've heard her tell friends, "I want you to come to my house. My father is in a wheelchair, and wow! You should see our elevator and our lift. You can ride in his chair." She makes them all kind of envious so I think she has done a pretty good job of working that through.

### **Sexuality**

Yvonne Duffy

In terms of the study I did for my book, 21 of the 77 women studied had polio. The women who had polio didn't seem to have any particular problems that wouldn't occur with other women. Most who talked about positions said that they preferred side or stomach positions because of spinal curvatures.

I like to look at sexuality in its broadest range, socialization, self-image, and so on. Of the 21 women, 13 of them had really strong or above average self-image. Ten of the 13 had had polio before the age of puberty.

One of the problems reported most frequently was the difficulty for disabled children to find out anything about sex. Parents tend to think of us as being children forever and a lot of us grew up with rather strange ideas about sex. My mother told me about the birds and bees at the usual time that everybody learns about sex, but told me not to bother my head about it because I wouldn't be able to do it anyway. That was untrue for me and for all the women in my study. Such false information can really hurt us.

It is really important to make sure that disabled children have a good factual sex education program.

### **Fertility for Spinal Cord Injured Persons**

Lauro S. Halstead

Fertility is not a problem for polio survivors that I am aware of. However, because this conference is for persons interested not only in polio but also in problems common to many types of long-term handicaps, a brief discussion of the problem and status of infertility in persons with spinal cord injury (SCI) would be relevant. Because SCI does not appear to impair fertility in women, the focus of this review will be limited to the many ways in which spinal injury alters fertility in men.

Along with the development of the polio vaccines in the mid 1950s, the improved prognosis for spinal cord injured patients ranks among one of the major medical accomplishments of the past 50 years. The reasons for this improved prognosis are primarily the result of better understanding of the extensive pathologic changes resulting from the neurologic trauma and of improved coordination of care from the time of injury throughout the course of rehabilitation. Although many spinal

cord injured persons reenter the mainstream of society and live full and productive lives, a major remaining problem is that of altered sexual function and infertility.

In 1983 a man who sustained a spinal injury had a less than 10% chance of fathering children. This is because of combination of problems, including difficulties with erection, absent or altered ejaculation, and impaired sperm production.

While the problems of impotence and failure of ejaculation can be explained on a neurologic basis, impairment of normal sperm production is not well understood. Biopsies of the testicles have shown various types of abnormalities in more than 50% of patients. Interestingly, however, these changes do not appear to be related to the length of time elapsed since injury. The major changes noted on biopsy are related to abnormal semen quality, which, of course, has major implications for fathering children. The reason for these changes is currently unclear. Several possible explanations include alterations of normal nerve supply to the testes, changes in local as well as total body temperature, and infections and various other complications in the lower urinary tract. However, it is of interest that there has been at least one study that was unable to verify an increase in scrotal and testicular temperature in spinal cord injured patients, and there is no correlation between biopsy findings of the testes and a history of various infections or complications of the lower urinary tract.

Finally, changes in the body's hormones that regulate sperm production and normal sexual activity have been extensively studied. There appears to be a transient alteration in some hormones during the first few months following injury. However, there appears to be no permanent change in the hormones that regulate sperm development, so at the present time, hormonal changes do not appear to play a major role in those patients who fail to produce normal sperm.

For patients who can produce normal sperm, however, there is often the problem of inadequate or absent ejaculation. It is with this problem that we are primarily concerned today. At the present time, there are three approaches for inducing ejaculation in patients with spinal cord injury: electro-ejaculation, chemical ejaculation, and ejaculation using vibration. Most of the reports in the literature have dealt with either electro-ejaculation or chemical ejaculation.

**ELECTRO-EJACULATION.** Electro-ejaculation was first described in 1968 and involves inserting a probe into the rectum to stimulate electrically the anatomic structures adjacent to the rectum that contains the semen. Sperm obtained with this technique are then used to impregnate artificially the subject's spouse. While there has been world-



wide interest in this approach to producing ejaculation, the only reports of pregnancies have appeared in the European literature. A number of centers in this country are currently employing electro-ejaculation with varying degrees of success, but to date, to my knowledge no one in this country has reported a pregnancy using this technique. The major risks associated with electro-ejaculation include potential injury to the lining of the rectum where the probe is inserted, and induction of autonomic dysreflexia, characterized chiefly by a sharp elevation in blood pressure.

**CHEMICAL EJACULATION.** The second major technique to induce ejaculation in spinal cord patients uses a chemical known as neostigmine, which is injected into the spinal canal at the base of the spine. One to 3 hours after the injection, patients experience one or more spontaneous ejaculations. The exact mechanism whereby this drug causes ejaculation is not understood. This technique has also been used for artificial insemination, with reports of several pregnancies. Again, all of these reports have appeared in the European literature, and because of some initial complications with this technique many years ago, it has never gained acceptance in this country. The major complication associated with chemical ejaculation, as with electro-ejaculation, is autonomic dysreflexia or hypertension; because of major advances in controlling hypertension in recent years, it is now possible to control fully the adverse effects of chemical ejaculation.

**TIRR/BAYLOR FERTILITY PROGRAM.** For this reason, we decided several years ago, in conjunction with Dr. Larry Lipshultz at Baylor College of Medicine, to establish a fertility program to reevaluate the potential of chemical ejaculation in spinal cord injured men. This program consists of an initial interview and physical examination, and then a series of screening tests, including determination of sex hormone levels and testicular biopsy. From among the married subjects who had normal hormone levels and biopsy results, five have undergone chemical ejaculation with neostigmine.

In each instance the subject was admitted overnight to the hospital and appropriate procedures were employed to minimize adverse side effects and maintain the blood pressure in normal ranges at all times.

The five patients studied ranged in age from 22 to 35 years, with a mean of 29 years. Two patients had cervical injuries or injuries to the neck, and three had injuries in the thoracic region. Prior to chemical ejaculation, all five patients reported experiencing reflex erections and intercourse.

The results from this initial experience have been both encouraging and discouraging. Semen obtained from each chemical ejaculation was used

for artificial insemination in the subject's spouse. The amount of semen varied from 1 million to 150 million sperm and the motility from 5% to 40%. In general, it is felt that 100 to 200 million sperm per milliliter are needed for conception, with a motility percent of at least 40%. Ironically, the wife of the subject with the best quality semen had not ovulated at the time of artificial insemination. For this reason, we are now starting to monitor the wives with ultrasound, which enables us to identify when the wife is preparing to ovulate. By using special medications (Clomid or human chorionic gonadotropin), it is possible to help induce ovulation at a predictable time to coincide with chemical ejaculation.

**DISCUSSION.** It is curious that with all our technology in this country we have been unsuccessful with both electro-ejaculation and chemical ejaculation while there have been pregnancies reported using both techniques by Europeans. In comparing the two techniques, they both can produce the same major side effects (dysreflexia, or high blood pressure), although if performed in a hospital with proper precautions, the dysreflexia can be controlled.

I have not seen a breakdown in the cost figures for electro-ejaculation, but in our program the total cost ranges from \$1,500 to \$2,500, with the major expenses being the cost of hospitalization, the cost for the initial screening tests, and the cost of a specialist to help monitor and control the blood pressure.

We feel the ability to monitor ovulation in the spouse represents an important step in eventually achieving success in this group of patients. To our knowledge, this has not been fully used elsewhere. The big advantage is that it minimizes the number of times a patient needs to undergo artificial ejaculation, reducing cost, discomfort, and inconvenience.

Finally, there are several additional unexplored approaches that may enhance our ability to help spinal cord injured men father children. One combines the use of either chemical ejaculation or electro-ejaculation with vibratory techniques, and the second is the use of in vitro fertilization (IVF), or the technique used for producing "test tube babies." This latter approach has the advantage of requiring many fewer sperm and would provide control over some of the elements now left to chance. Finally, many patients ask about the possibility of freezing their semen in a sperm bank for future use. A group in France recently reported their experience with this technique, and, unfortunately, their results were discouraging. They discovered that the motility of the sperm was very low after thawing the frozen semen.

#### RECOMMENDATIONS.

- We need more information on why sperm production is impaired in spinal cord injured subjects.
- We need to clarify why the Europeans have been successful while investigators in this country remain unsuccessful.
- We need to gain more experience with both electro-ejaculation and chemical ejaculation to discover the best way of optimizing the production of quality sperm.
- We need to monitor the spouse's ovulatory cycle so that ovulation can be induced to coincide with induced ejaculation.
- We need to explore the applicability of in vitro fertilization, which has opened a whole new dimension of treating noninjured persons with infertility problems.
- We need to initiate and continue a discussion of the humanistic and ethical issues involved in manipulating nature in ways that impact on people's lives in very far-reaching and yet very personal ways.

# INDEPENDENT LIVING

## SUMMARY

Gini Laurie related her 35 years of observing the experiences of polio survivors living independently to the independent living movement.

Phyllis Rubenfeld recalled that the American Coalition of Citizens with Disabilities was founded in 1974 by a group of disabled people who recognized that all people with disabilities must work together to secure independence and civil rights. The veto of the Rehabilitation Act of 1973 by President Nixon and the demonstrations in 1977 to implement Section 504 were the catalysts that strengthened "the movement to seek full, civil, and human rights for all people with disabilities."

The history of the independent living movement was told by one of its founders, Ed Roberts. "From the beginning we were political. Now the 23 centers in California are the most important political network in our state and the state is putting up about \$4½ million for the center's core money. . . . If we could organize all disabled people and elderly and children and all who are devalued, we could be one of the most powerful forces on earth."

Judy Heumann summarized the philosophy of the independent living movement as "... a civil rights movement. . . . The centers are vehicles to enable people to become free, to provide innova-

tive programs to ensure that no one needs to be living in an institution."

Jim DeJong described the importance of the recent development of the National Coalition of Independent Living Programs (NCILP) as a means of trading information and technical assistance as well as of developing the political aspects of the future.

The future of the movement was visualized by Ray Zanella and Irving Zola. "The movement," says Zanella, "is the active expression of consumerism and of our own civil rights. . . . As it grows, we must watch out that there are enough people to develop within ranks to replace leaders, . . . and that we are not pigeonholed and directed away from controlling our own lives."

Dr. Zola emphasized, "We are a political movement because we are interested in promoting change in attitudes, in barriers, in opportunities. . . . We are political because the professions out there are in certain ways fighting over us and our turf, because in some states we are fighting over who has control over the personal care attendant, because we must be aware of the peril of pitting one disease group against another."

### Polio Foreshadowing

Gini Laurie

The foreshadowings of independent living were in California back in 1953 when Los Angeles County realized that its Rancho Los Amigos Hospital had 158 ventilator-dependent polio survivors unnecessarily occupying \$37-a-day hospital beds when they could be cared for at home for \$10 a day. A home care system was set up. In effect, the system was 158 one-person self-directed independent living centers. Other polio centers around the country copied this money-saving plan and sent their patients home, many of them with about \$300 a month from the March of Dimes, to hire and train their own attendants. This utopia lasted about 6 years until July 1959, when the success of the vaccine curtailed donations to the March of Dimes. The centers were closed and the home care funding stopped.

Then the scrounge for attendant care monies began. Our *Gazette*, the national and international hub of polio information, stirred its readers all across the United States to write to their congressmen to try to effect national attendant care legislation. The only tangible result was funding by the Department of Health, Education, and Welfare

of a survey and report by Saad Nagi, PhD, published in 1962. The report concluded that "many need but cannot afford more care" and "long-term disabilities require long-term aid."

A similar campaign in California was more successful. Dr. Leon Lewis, the medical director of the center at Fairmount Hospital and the polio survivors of the San Francisco Bay area led a campaign that effected attendant care legislation in California. Thus in 1960 the way was paved for the independent living movement to be started a decade later in the same area by one of Dr. Lewis' ex-patients, Ed Roberts. Ed Roberts and John Hessler made the big leap from one-person independent living systems of services to a system for all disabled persons of all ages at a center for independent living. But their system of service might have stayed in California if there had not been developing simultaneously a spirit for human rights expressed in coalitions of organizations for all types of disabilities and encouraged by specialized and generalized disability publications.

## **ACCD Influence**

Phyllis Rubenfeld

Until now we have not had our own disability group identity, as have the National Association of the Deaf, the American Council of the Blind, or the National Spinal Cord Injury Association. We have, however, shared with these groups a large identity based on those issues which we all have in common. Why haven't we had our own group identity? Let us look at our history.

In 1955 Jonah Salk successfully began the process of irradiating polio in the United States. The March of Dimes, believing that it had fulfilled its mission, dismissed its obligation to provide ongoing research for those of us who are disabled because of polio. The medical establishment turned its efforts away from us for the same reason. In hindsight these actions have created a situation that places us in an uncertain and frightening position. We are now experiencing medical and physical difficulties that we must face without adequate scientific knowledge. It is critical for us as people who have had polio to become organized and remain united to address the issues identified at this conference.

One of the outcomes of this meeting should be the formal establishment of a group for people who have had polio. We must also be aware that although we are different from other disabled people, we share a common bond that unites all of us. It was this recognition that served as the impetus for the founding of the American Coalition of Citizens with Disabilities (ACCD) in 1974. ACCD is a national coalition organized by a group of people with various disabilities who believed that we must join together to secure our independence and civil rights. Not wanting to lose our individual group identity, we decided on the organizational structure of a coalition. We recognized that as disabled people our goal is integration into the mainstream, because self-determination is crucial to our ability to function in society at large.

The social and political climate in the early 1970's encouraged disabled people to begin to speak out and not continue to be seen in the traditional passive and dependent role that stereotyped us. We organized around the 1973 Rehabilitation Act, which had been vetoed by President Nixon. That legislation was a unifying issue because it contained elements that all people with disabilities could relate to, namely the antidiscrimination provision of Title VII. During its first year of existence, ACCD organized protests against the presidential veto, and eventually Congress overrode the veto. In keeping with our demonstrated commitment to this legislation we continued to organize and push for compliance. For the first time in our history, in the spring of 1977, demonstrations and sit-ins were held simultaneously across the country to secure

the signing of the regulations to implement Section 504, the antidiscrimination provision of Title VII.

Unfortunately the current political and economic climate forces ACCD to direct its efforts to maintaining what we achieved in the 1970's. It is difficult to move forward when we are in danger of losing what we recently attained. It is incumbent on all of us as disabled people and as those who support our movement to continue the vigil to seek full civil and human rights for all people with disabilities. I look forward to the time when those of us who have had polio organize ourselves. Only through our collective efforts will we be able to achieve our goal. To maximize the potential political clout we have gained in coming together for this conference, it is necessary to join the larger disability rights movement. In coalitions we lend strength to the causes of others and gain support for our own, thereby achieving what is best for all people with disabilities.

## **History**

Edward V. Roberts

The reason the independent living movement is becoming so powerful and political today is that we started it to help ourselves become independent. We were going to the University of California at Berkeley and learning how to be revolutionaries during the 1960's. We learned how to organize a community, shutting down the campus a few times. We knew that if we were ever going to leave that student dorm and really live in the community, we had to set up a service and advocacy system that we could run and that other disabled people could join. We had to free each other.

We began with a core of services in attendant care, how to find an attendant, how to do it collectively. We had an attendant pool with literally hundreds of students and others who wanted part-time jobs, and we could choose who we wanted to live with us. From that we started our own wheelchair repair. It took 6 months to a year to get your wheelchair repaired if you sent it to E&J in Los Angeles. You lost your electric chair for 6 months, you were in bed with no mobility. So we designed a system as a disabled student program, and within a very short time we had calls from all over the world about what we were doing, how we did it, and what it took to make it work.

That was 1970. Then, John Hessler, a spinal cord quadriplegic, took over as director of that program, and that program nurtured the CIL. Our money from the federal government came because we wrote the regulations on the Students Special Services Program. The money was available only to students. Within about a year we were serving about 50% students and 50% people in the Bay area and all over. It just evolved. We began to find out that we knew the welfare bureaucracy rules

pretty well and could find opportunities to be independent. We raised the attendant care allowances to the maximum. People who came into our camp were taught to be their own advocates.

I'm not sure we ever dreamed how far this would go, but since it worked for us and we were very severely disabled, it seemed like it would work for everybody. Those of us there had many different disabilities, so it was natural to include all people with disabilities.

We felt people viewed us as vegetables, or oddities. I remember going to the university in 1962. I remember what a traumatic thing it was for the university to let me in. They couldn't reject me. There are now probably 800 disabled students at Berkeley.

A pioneer in education, Martha Redden, helped us to open up universities across the country. I believe the independent living movement came from the campuses as we began to exercise our freedom. We delivered service from a small, poor, two-bedroom apartment with one elevator. Within 2 years we had raised \$2 million, mostly in grants.

We didn't really know how to obtain fees for service, and we evolved into a political program. I think we knew from the beginning that services were great but unless we were political, unless we were seen out and about. The Berkeley City Hall was totally inaccessible. We sat there during the political meetings with signs, and our political power made the City Hall accessible. Then the City of Berkeley became accessible, and as we began to move, people began to join us. When I became rehabilitation director we had a great deal of money directed toward establishing centers. I'm not sure how many we have in California, maybe 23 right now. Those things are the most important political network in our state — the most powerful and the most respected. When those centers ask for or advocate against something, they are heeded because we have political power, because we help people in their elections, because we donate money to campaigns, because we supported and worked with them; when we ask for something they often give it to us.

Despite the incredible budget problems in California now, the state is putting up almost \$4½ million for Independent Living Center core money. That is important because you can't live on grants forever. Those of you who are thinking about starting new independent living centers, remember that a grant can get you started, but you have to find long-term permanent funding. We hope the 1978 Rehabilitation Amendments will do this, but the supply of money has not increased much over the years. If you don't increase your programs quickly, it is very difficult to obtain long-term funding.

Overall I think the movement started from trying

to be free ourselves and wound up freeing thousands of people. It is going to do even more. I agree with Justin Dart on that. The reason it is so powerful is that it is an indigenous movement. You and I are doing it, not others telling us what to do. You and I are helping to make each other free. It begins with a very positive attitude that says disability is not the most important thing at all; motivation is. It's the belief in yourself, having people around you who believe you can do something with your life. Each of us is an example of what can happen when you believe in yourself.

There wasn't anything I didn't learn at Berkeley. It was like being reborn, and it is continually happening. Through international travel and seeing other countries, I'm beginning to feel that same feeling, that incredible feeling of power and knowledge that if we organize together and bring all disabled people, elderly and children who are devalued, we could be one of the most powerful forces on earth. This country has perhaps 66 million disabled people. Can you imagine the political power we would have together if we allied ourselves closely with the elderly? That would be more than 100 million people in this country alone. We are the majority; we knew that in the beginning, and I think some of our dream for freedom is beginning to come true. We all have the desire for freedom, and now even the most severely and profoundly disabled people in our society are beginning to understand that they can contribute tremendously.

I'm proud of Gini and all of you pioneers. This movement, this belief that we can be free and can free others, is really just beginning, compared to most political movements. It is only 10 years old.

If you don't have an independent living center in your community, start one. You are powerful enough; do it in your own communities. If you need technical assistance, there are plenty of people now who know exactly how to set one up. The future is there for all people with disabilities and all of us in the mainstream, not on the outside looking in. We are going to make significant contributions to this society, things we have not dreamed of. We are going to give disability a new image, so instead of seeing us as weak and unable, maybe we should be astronauts, movie stars, people who are very visible and very successful.

### **Philosophy**

Judy Heumann

The philosophy of the independent living movement is a civil rights movement. I personally feel that it is important to hold this view because we're trying to do away with discrimination against disabled individuals. So far we have failed to acknowledge that what has existed for disabled people is discrimination.

The philosophy therefore must be that we empower ourselves and other disabled people. The independent living movement itself must speak for all persons with disabilities.

We are a social movement, a political movement, a movement that truly wishes to integrate people. The independent living centers are a vehicle to enable people to become free and to provide innovative programs to ensure that we no longer hear that anyone is a "have not," that we no longer hear that there are any reasons why anyone needs to be living in an institution.

It is an incredibly difficult problem to expect people who have few alternatives to really be able to move forward. The philosophy of our movement must be that of a civil rights movement, as movement of freedom for all people and a movement that recognizes that everyone of us can contribute, is contributing, and must continue to contribute.

The whole scope of our movement is integration, not excluding people who are nondisabled. At the Berkeley center we very early reserved the top jobs for disabled people because we couldn't get jobs anywhere else. I think that is still a good idea because it is our training ground, and one of the few places where you can get top-level management and budgeting experience. But we don't just hire disabled people; that isn't the idea. The leadership should be disabled people, but there are many individuals who are as good at serving as disabled persons are. We need to work together, our whole society, and the whole philosophy on which the independent movement was built involved mainstreaming and integraton. We should continue to preserve those jobs at the top level of the independent living centers for disabled people. Discrimination is a huge fight within every organization.

#### **National Organization**

Jim DeJong

At our first meeting in Washington D.C., we gathered well over 50 independent living programs out of the 150 presently funded. One-third are now part of the National Council of Independent Living Programs (NCILP).

The National Council realizes that we must join together to trade pragmatic information and gain technical assistance from one another's programs. We also realize that we must be in the forefront of the political movement and must continually inform and educate our congressional leaders.

#### **A Massachusetts Center**

Charles Carr

I started the Northeast Independent Living center. We were an outgrowth of the Title VII initiative and the majority of my funding is through Title VII. My agency is peer controlled in all levels of management, board, and direct service. By peer controlled

I mean that disabled persons run the agency, provide the services, and are also involved in the politics that eventually provide the funding. We are very much involved in peer counselling and attendant care.

We have a viable center that covers all the bases in terms of independent living, and we hope that when Title VII is hashed out and the funding eventually ends, we will still be self-sufficient. We have opted for fee for services in addition to private United Way money and some state funding in our VR budget for independent living. We also do fundraising. We know we could fall flat on our faces tomorrow and planned in advance for that. We're trying, and we have a very active constituency in Massachusetts. At any given time, we can generally pull together from 100 to 200 individuals within a week to lobby for or against specific issues.

#### **The Politics**

Irving Kenneth Zola

The independent living movement is a political one because we are interested in promoting change — change in attitudes, change in barriers, change in opportunities. We are political because we must ask who we represent and to what extent we are going to engage in outreach so that the populations that attend this kind of convention and others will not be exclusively of one racial, economic, or other similar group. We are political because ideologically we speak of the quality of life and thus challenge some deeply held values in America that measure the worth of an individual by the amount of physical work done or the income earned. We are political because we speak of economic priorities. We are political because every encounter between us and the health care system involves a differential of power where one person, or unit, in this encounter has more access to resource and information than the other, and while we would like to talk about negotiation, it is often more likely a fight. We are political because the professions are fighting over us and our turf. The physical therapists are trying to gain the possibility to have independent referrals to them rather than going through the medical world. In varying states, we are fighting about who has control over the personal care attendant, and the word is *control*. We are political because we must be aware of the "divide and conquer" philosophy in the United States that pits one disease group against the other and may push us into trying to show that one disability is worse than another. Thus we must be political in always stressing alliances of all disabilities to every disease group that exists, and we must be political because we must organize into a political constituency to whom the government must be responsible and accountable.

## **The Future**

Ray Zanella

The independent living movement is the active expression of consumerism. It provides social services, direct services to individuals and to groups of people, but it is also an expression of our civil rights. The gains we have made have been largely because of our own voicing of our consumerism. As disabled people we have demanded that the systems be responsive to us.

Those in other countries are experiencing the early growths of independent living. Our movement is largely dependent on money, grant money, unfortunately. What I've seen is a co-optation of consumerism. Other countries have monies appropriated for independent living, and we have to be careful about a couple of things. Loss of consumerism is the most important. As we develop as consumers, many of us have moved away from our independent living centers to become leaders, and we haven't allowed enough people to develop within our own ranks to replace us. Because we've had a large influx of new monies, the centers apparently have hired many people from outside of the movement who really don't understand what hap-

pened in California 10 years ago and in all of our states within the last couple of years. We have to be sure that when we talk about consumerism, we have direction, we will not sell out. As new money is created, we see more efforts for fee for services and a greater need for accountability, more bureaucracy, and more structure. This may be good in some ways, but it tends to be oppressive. Let's not let our independent living movement do that to us.

I also fear that as new independent living money is created there will be a pigeonholing of our clients. As money is generated, people who would normally go into vocational rehabilitation training programs may be diverted into independent living and not into vocational rehabilitation also. Vocational rehabilitation from my perspective is a very small part of independent living; it is a component. It can't be separated.

Independent living is the expression that we all want, including jobs and economic security and family life and civil rights. Let us make sure that we're not pigeonholed and directed away from jobs and away from controlling our own lives.

# FORUM FOR INTERNATIONAL INTERCHANGE

## SUMMARY

Each speaker summarized the status of disabled persons in his/her own country.

*Australia.* "The consumer movement," said Rosina Grosse, "is in the embryonic state in Australia . . . When some of us went to the Disabled Peoples' International Congress in Singapore we were inspired to make a total commitment to the new concept of independent living . . . There will be much achieved in Australia in the next few years."

*Canada, Manitoba.* Theresa Ducharme described the problems she encountered when, after being hospitalized for many years, she wished to marry and move into the community. Her solutions were the basis of a new government home care program that funds individuals to hire and train their own attendants.

*Canada, Ontario.* "In terms of independent living centers," said Audrey King, "Canada is not as advanced as the United States but many of the problems are very similar: A lot of professionals are trading on the phrase independent living . . . There aren't enough disabled people involved actively . . . What the professionals say the disabled need is totally different from what disabled people say they need."

*El Salvador.* "The people live mostly with their families," said Eileen Giron, "and they are taken care of by them . . . Most of them live in very bad conditions. They don't have any wheelchairs, so they have to stay at home in bed and they are considered as sick people and not able to do a job . . . Rehabilitation services and education are only in the capital city."

*England.* "There are dilemmas," stated Selwyn Goldsmith, "in both cultures . . . In the United States it is about equal treatment and normalization; on our side, it is about special treatment . . . We have been shifting our orientations in Britain . . . about programs of house renovations and about assisting people to remain in their own homes where they can be supported with the services coming in from the outside rather than the service being provided in-house."

*Germany.* August Rüggeberg arranged an international independent living conference in Munich in 1982. As a result, his organization, VIE, is planning to adapt American concepts of independent

living centers to Germany. "We have learned during this conference," he said, "the importance of international exchange of experience and people . . . We in Germany are well prepared to receive disabled people and we are very much interested in sending disabled people to other countries to learn what independent living means around the world."

*India.* "The movement of rehabilitation started about 30 years ago," stated Mrs. Chaukar, "and it is gaining momentum but the efforts are concentrated only in the large cities and have not reached the rural areas. The International Year of the Disabled awakened the interest of the government in the welfare of disabled people."

*Japan.* "Situations are different in each Asian country but most still have a large family system," said Yukiko Oka. "This year Judy Heumann had seminars in the five largest cities in Japan so we are informed about the American centers and the concept is ideal. However, I think we should seek an Asian type of independent living."

*Mexico.* Mrs. Eileen Van Albert, the doyenne of disabled persons in Mexico, has lived there for 21 years. She has watched the ebb and flow of disabled persons moving to Mexico because of the cheap attendants, then leaving when costs were inflated.

*South Africa.* "We don't have any government funding," said Kathy Jagoe, "so people tend to go it alone. We are having our first Congress of Disabled People in September this year. It will be the first time all disabled people of all races will get together and start talking about issues that affect all of us."

*Sweden.* Adolf Ratzka discussed the gap between the disabled and the rest of the population. "Only 20% are employed," he says, "compared to 68% of nondisabled in the same age bracket; the disabled are four times as likely to be socially isolated . . . Most of the leaders of the disabled movement in Sweden are nondisabled . . . Too much research is carried out on issues relevant to us without consumer control . . . I am appalled at all the begging and all this gratefulness to the March of Dimes and similar organizations because you happen to get a ventilator . . . I am surprised that nobody at this conference has proposed a resolution that what you need is national health insurance."



## Sweden

Adolf Ratzka

I will concentrate on the gap between the disabled and the rest of the population in a few areas. First, employment. Only 20% of all physically disabled people are employed in Sweden, as opposed to 60% among nondisabled in the same age bracket, between 16 and 64. Second, in education, only 4% of all the physically disabled attended college, as opposed to 15% in all of Sweden. Third, recent government statistics show that the physically disabled are four times as likely to be socially isolated as the rest of the nation.

Overall we are still second-class citizens in Sweden, but Sweden has developed some interesting programs, regarding accessibility. Since 1977 all new construction has to be accessible, which means that buildings of more than 2 floors have to have elevators, wide doors, toilets, and everything else you need. This includes public buildings, restaurants, shops, places of employment like offices, universities, schools, and housing.

Also, Sweden has a national health insurance so you receive free medical services. Surgery is free to you, so family finances do not suffer. The same is true for technical aids.

What I miss in Sweden is consumer involvement at the policy-making level. Most of the leaders of the disabled movement in Sweden are non-disabled. Sweden sent 12 delegates to the Disabled Persons International meeting in Singapore, and only 2 were disabled. What we need in Sweden is consumerism and self-determination. As a researcher I am appalled at how much research is carried out on issues relevant to us, yet without consumer control.

## United Kingdom

Selwyn Goldsmith

First in the United States there is a remarkable concentration of effort on macro-environment facilities, on making your environments universally accessible to handicapped people. There is relatively less concentration of effort on micro-environmental programs, particularly housing. This impresses me, coming from western Europe, where in the main our services for disabled people emphasize much more the housing programs than the external environment programs. Second, the housing program here concentrates on political activity, the independent living programs. In the United Kingdom we try to improve institutional living. Third, in the United States, equal treatment and normalization are the focus, whereas on our side we focus on special treatment, or traditionally, discriminatory services and programs, special programs. Fourth, over here there is a brand of political idealism, of willingness to make leaps to shift things; on our side there is more pragmatism, gradualism, incrementalism.

There are dilemmas on both sides: How do we shift toward the kinds of programs that we would like to be achieving on both sides? How do we fill the gaps and make up for the deficits we see? In practice very little has been achieved in America over recent years in the evolution of attendant care programs. We're constantly citing California, and it is dismaying for me to come here and find that only California has made progress, and the rest of the country has not followed suit. Why not? In Britain we have done a good deal of work recently about shifting our orientation. We have not gone for the kind of congregate living in Sweden or the schemes we see developing in Holland. We're looking much more at assisting people to remain in their own homes, and to be supported there through services coming in from outside, rather than services being provided in the house. We're developing programs of housing renovations, where there seems to be no such service in America. It is interesting that whereas the Thatcher government favors removing the whole public responsibility for programs and introducing private sector initiative, much as Reagan favors, this isn't happening, at least in any substantial realizable amount. But on the other hand we have found that through the Housing Ministry this government funds very substantial increases in house renovation grants. If you are disabled, for a typical house renovation costing up to ten thousand pounds, or \$15,000, 75% is a straight government grant. For disabled people who are receiving welfare, 90% is a straight government grant. This is the kind of program the Thatcher government advocates, and we are allying ourselves as best we can with the promotion and development of independent living care attendant programs.

## Canada

Theresa Ducharme

A government program called Home Care based in all major hospitals in Manitoba has required expansion to accommodate respiratory patients. I struggled to get personal care attendants and home orderly service to live more independently. The government Home Care program offered three choices. One, live in a common law relationship. This option was strongly advised because then both partners would receive separate public assistance. Two, institutionalization, which means returning home on my husband's days off. Three, the provision of a male attendant who could lift me as well as provide personal care. None of these alternatives were acceptable to us. Eventually, the government changed its program to accommodate marriage and family life by providing funds to the disabled person to hire and fire attendants.

## Canada

Audrey J. King

Independent living in Canada exists pretty much as it does in any other developed country. It shows the same structure in the sense that people who tend to be involved in the philosophy are younger, more intelligent, more assertive individuals. It tends to be more focused in the urban rather than rural areas and to show the same relationships, the same dissatisfaction with the bureaucratic, political, and rehabilitation professionals, who are seen as impositions of power and control. The same issues are being addressed: housing, transportation, employment, and so on.

There are many consumer groups all across Canada. They are organized locally, provincially, nationally, and internationally through Disabled Peoples' International (DPI). In Ontario the provincial group, or rather the national group as it is called, is the Coalition of Provincial Organizations of the Handicapped (COPOH). In Newfoundland, a maritime seafaring province, their particular group is called the Coalition of the Disabled (COD). Their logo is a codfish with a crutch. In terms of independent living centers, Canada isn't as far as the United States, although again there is great variation. A lot of professionals are trading on the phrase *independent living*, and you find independent living centers and aids for independent living. In Toronto a group of OT's are trying to set up an independent living center they say will have a storefront approach, but there really aren't many disabled people actively involved.

One important development in 1981 was a federal task force, created to look into the needs of the handicapped across Canada. David Smith, who is a member of Parliament, travelled coast to coast holding public hearings and getting the input of professionals, agencies, consumers, and so on. When he came back he said that he had held many hearings and was impressed by the fact that what the rehabilitation professionals and the so-called experts said disabled people needed was totally different from what disabled people said they needed. His full intention was to return to Ottawa and put all the money and the power in the hands of consumers, because he felt that their sincerity, their knowledge, and their experience best qualified them to handle these programs. The Ministry of Health and Ministries of Community Social Services are now experiencing increasing cutbacks.

At the moment in Canada there is federal money going toward consumer groups directly. As a rehabilitation professional and a disabled consumer, I am concerned about the need to bridge the gaps and try to change the attitudes of some rehabilitation professionals so they can fully realize that we are contrasting traditional rehabilitation and the professional approach with independent living.

## Australia

Rosina M. Grosse

We have independent living centers in Australia. They are located in hospital grounds, staffed by occupational therapists. But they are merely displays of aids and equipment that disabled people can only enter with a physician's referral.

The consumer movement in Australia is in the embryonic stage. Therefore the independent living movement is a very new concept. Disabled people are now becoming involved in the management of support services such as home care, which is parallel to your homemaker service. Our federal government has been influenced in all their decisions concerning disabled people by the Australian Council for the Rehabilitation of Disabled, which has not involved disabled consumers until very recently. The status of technical aids for the disabled is far behind the rest of the world. Three weeks ago I received an LP3 ventilator and it was the first of its kind in Australia.

Royal Year of Disabled Peoples really began the coalition movement of disabled people in Australia. In 1981 35 disabled people travelled to the first World Congress for Disabled Peoples' International in Singapore. The interchange that took place there really inspired some of us to make a total commitment to the concept of independent living.

We're working on mainstreaming disabled people in education and in employment. Our federal government in consultation with the Australian Council for the Rehabilitation of Disabled, has introduced several new initiatives. The federal scheme for provision of aids to disabled people who were not eligible under any other program covers basically anyone who doesn't receive social security or veteran's pensions. However, while the concept is good, it falls down in administration because each state administers its own program and often the system is inefficient. I administer the program in my part of New South Wales so it is very efficient.

The federal government in April this year commenced a transport allowance, \$10 per week to people who are employed, rehabilitation clients, or attending activity therapy centers for 20 hours or more a week. A pilot attendant care program has been announced and will begin shortly. In our last federal budget, \$100,000 was allocated to this pilot project, which is to be administered through the New South Wales Home Care Service. The \$100,000 is to cover client needs, administration, assessment by occupational therapists, and research, so only about 24 disabled people will be able to participate in the pilot project. It will last 12 months. We in the movement are exerting pressure to have direct payment made to at least half of the participants. Some of the restrictions in the pilot program are that the people must be in the age

group 16 to 60, working or have good employment prospects. People with combined physical and intellectual disabilities are excluded. The attendants cannot perform household or food preparation tasks; they can put someone to bed but not give them a sandwich first. They can help the disabled people into transport but not accompany them to work. There is a national monitoring committee composed of consumers and some very weighty bureaucrats. At their first meeting in February, there was no paperwork whatsoever provided before the 1½-hour meeting. They were obviously set up to be a rubber stamp committee. But some people had travelled half across the continent for that meeting, and our consumers on that committee have provided the Social Security Department with a few surprises. When our pilot program was becoming a reality several unions expressed interest in expanding their membership to cover the personal care attendants. We were horrified when the nurses' association joined the demarcation dispute before the industrial commission claimed that only they should provide coverage.

Disabled people at a public meeting the following Sunday decided to demonstrate outside the nurses' association. We had less than 2 days. We sent out a press release titled "Nurses Cripple Disabled Program," so we got terrific media coverage. We had about 80 disabled people at the demonstration. We also have four major newspapers and three TV channels, one of which gave national coverage. The nurses assured us that if the attendants came under their union, they would not restrict attendants to nursing professionals; however, when I asked their secretary in front of the national TV camera if they would assure us on the air that the association would not alter their attitude in a few years' time, she could not make that commitment. We stated to our nation that we had the right to say who would put hands on our bodies. They argued that to hand a blind person a bottle of green pills as asked for was a nursing duty.

Our demonstration was a great success. We demonstrated an assertiveness and because of the publicity and community support, the nurses withdrew. This was for many of us a baptism of fire, but fire that stayed alight.

We are also working to remove our intellectually disadvantaged citizens, I believe you call them developmentally delayed, from psychiatric institutions.

There will be much achieved in Australia in the next few years, and I believe that the eyes of the world will eventually turn to Australia to learn from what we have achieved throughout our nation. Through DPI in Australia we will ensure that services and programs will be nationwide. The independent living movement will have a short-term

pregnancy with no birth defects. I hope at the next international conference to come back to you and report on a successful delivery.

## Germany

August Rüggeberg

From 1974 to 1977 I was educational director of Pfennigparade, a huge rehabilitation center in Munich. We had about 12 respiratory polio people clustered together in a special intensive care ward. When we as nonphysicians tried to integrate this subgroup into the rest of that institutional community, to simply scatter them over the rest of the house and dissolve that special care ward, we were told by professionals that this was simply impossible and we as laymen were unable to judge the dangers in it. If only we had known of the *Gazette* at that time! As a result of this German institutionalism and professionalism, we started to build up VIE, the organization I am representing here, which is mainly giving attendant care services, making attendant referral, and offering some advice for the independence of severely disabled people in the Munich area.

Among setbacks in bringing up this first German independence scheme, there was a trial in court of some disabled people who had to struggle to get the social welfare authorities to pay for their costs of home care, although these costs were nearly 30% lower than the formal costs of residential care. As a result of an international independent living conference we organized in Munich last year, we formulated a new scheme that aims at importing and adapting American concepts of independent living centers to Germany. We are here at this conference because we want to send a few people to the United States next year to give them the opportunity to work in various centers for independent living for a few months. After that they are to return to Germany to join in building up the first centers for independent living in our country. To demonstrate how narrow the basis for independent living is in Germany, it took us almost 1 year to get just 4 groups actively involved in this new pilot scheme.

Do not underestimate the importance of international exchange of experience and people. I wonder whether we could organize, as a result of this conference, a systematic international exchange of experience and disabled people. We in Germany are well prepared to receive disabled people from foreign countries, and we are very much interested in sending disabled people to other countries to learn what independent living means around the world.

This conference is unique and vivid proof of the feasibility of and rewards for disabled persons living independently. However, we have to bear in mind that we disabled people gathered here are really a privileged minority. Independent living as a

perspective for everybody is yet to be achieved in each country. We shouldn't forget that the vast majority of disabled people can afford neither the cost for coming here nor that for living independently. It is not so much the single individual who receives as much independence as he or she deserves, but it is the disabled community or society as a whole. The individual struggle for independence will be successful in the long run only if it is embedded in a broad political movement for civil rights and adequate economic self-sufficiency.

## Japan

Yukiko Oka

For Japanese disabled people, especially those who have severe disabilities, the American concept of independent living is an ideal. We are informed of the Center for Independent Living (CIL) through TV, newspapers, and magazines, maybe much better than are American citizens. In March this year a seminar was held in the five largest cities in Japan; we invited Judy Heumann and some members of the CIL in the United States. In each city there were large audiences, both disabled and nondisabled. However, travelling among the Asian countries I began to think that we should seek an Asian type of independent living.

Most of the countries in our region still have a large-family system. Industrial development has forced us to form a nucleus family but at the bottom of our hearts, we long for large families. This can be found only in Japan. To organize the Asian Pacific Regional Council Meeting of Disabled Peoples' International, I myself lived with disabled persons in Bangkok for 2 months last March and April. Because of the number of institutions in Bangkok, disabled people are forced to stay with their parents, and in most cases the families are too poor to let them sit idly during the daytime. According to the degree of their disability they ask to share certain work in the house. If they are fortunate enough to get a job outside the house, a member of the family helps them commute by driving a car. This over-protection easily invites spiritual dependencies.

Perhaps partly because of regarding the disabled as a member of their family and partly because of the Japanese nature of taking everything seriously, our volunteers are excellent. Many disabled who began to live independently in a small apartment room in Tokyo have volunteer attendants. They are much better than the home helpers dispatched by the government two or three times a week for only 2 or 3 hours.

We are still seeking the best ways to live independently. Situations differ in each Asian country, but I believe some common, ideal way for independent living can be found in the near future.

## Mexico

Eileen Van Albert

For a while there were about 150 disabled persons living in groups in big old homes and former motels in Guadalajara. But many who started out in the homes or motels developed enough nerve and moved out in groups of 3 or 4, renting their own homes and hiring their own aides. As others saw them move out, they thought if they can do it, so can we. So began American independent living in the area. The disabled did on their own, with no government intervention, just banding together. Eventually, so many moved out that the original homes and motels closed.

Many of the Americans have since returned to the States because the prices of aides have increased with inflation.

Now there are only two houses left. I rent a couple of rooms in my house and my brother rents a couple in his house.

Mexicans who are disabled are coming out of the closet a little bit, but for years you never saw a disabled person on the streets. I hope that within the next 3 years we'll have more and more Mexican disabled out on the street and driving their own hand-controlled cars.

## South Africa

Kathy Jagoe

Our situation is as different from Sweden as the Mexican situation is. We don't have any governmental funding like America does, and I doubt that we will have, until the apartheid system is scrapped. To give you an idea of the financial funding we do get, for whites we get approximately \$130 per month; for coloreds or Indians it is half of that and for blacks it is half of that again. People tend to go it alone and get private funding if they want to start up an organization. A few of us have had private funding to start the kind of projects that we work in, which is what I do and the reason I am here.

Another difference, as in the Australian situation, is that what South Africa calls *independent living centers* is not what America calls independent living centers. We've unfortunately been influenced by the Australians, and these centers are aids and information centers run and organized primarily by occupational therapists and physiotherapists.

Disabled people are beginning to become more outspoken. A few of us see the movement as a political movement, and it is becoming really exciting. We are having our first congress of disabled people in September this year; it will be the first time all disabled people of all races will get together and start talking about issues that affect all of us.

Until now, agencies with professional organization have been catering to disabled people according to their disability. Even self-help consumer or-

ganizations have focused on their own particular disabilities, which has both advantages and disadvantages. With regard to housing, there are still many people living in institutions and many in their own families, either with families acting as attendants or employing attendants. There is a collective housing group generally organized by the quadriplegic association of South Africa. In this a group of quadriplegics buys a house, organizes their own attendant care, and organizes their own transport. Not everybody agrees with group housing like this, but it obviously suits some people. A few of us have gone out on our own and are living totally independently with paid attendants.

#### **El Salvador**

Eileen Giron

The independent living movement is not widespread at all in El Salvador, which I believe is the case in most Latin American or developing countries. The people in El Salvador live mostly with their families who take care of them. A few people are very successful, but they are not involved in any kind of organization because they don't want to consider themselves as disabled people. Since they are very successful, they feel they are the same as anybody else. But these are very few people.

Most of the disabled live in very bad conditions. Rehabilitation services are available only in the capital city. In small cities there are no wheelchair services, or if they do have them, it is not easy to move about in a wheelchair. So they have to stay at home or in bed most of the time and are considered by other people as sick people.

In education, in rehabilitation services, the op-

portunities are very poor for the people and only available in the capital city. El Salvador has 5 million inhabitants, yet the school for the deaf only has room for 300 people. It is also very difficult for someone who is disabled to find a job because even if you have the skills, you are considered as someone who is sick and not able to do a job.

I work in a cooperative for disabled people, for teenagers. Most of them are there because we don't have enough money to put people in wheelchairs. The only people who can come to work for us live close. I am working with some other friends of mine, one is paraplegic and blind, and we are beginning to work on independent living. We are doing a very hard job.

#### **India**

M. A. Chaukar

Just last year we celebrated our silver jubilee at the All India Institute of Physical Medicine & Rehabilitation Center, so we can say that the movement of rehabilitation started about 30 years ago. It is gaining momentum, but efforts are concentrated only in the larger cities like Bombay, Delhi, and Calcutta; they have not reached the rural areas.

Because of the 1981 International Year of the Handicapped, the government is taking more and more interest in the welfare of handicapped people. They are making laws and regulations so that handicapped people can come out of their homes and start working and living independently. I feel that handicapped people really have made great strides in India.

# APPENDIX

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ISBN 0-931301-01-7 \$15.00

Printed in U.S.A.