

福 G.I.N.I. - GAZETTE INTERNATIONAL

INTERNATIONAL VENTILATOR USERS NETWORK

福

Fifth International
**POLIO AND
INDEPENDENT
LIVING
CONFERENCE**
St. Louis, Missouri

NETWORKING INSTITUTE 福 IPN - INTERNATIONAL

福 POLIO NETWORK - I.V.U.N.

Wednesday, May 31, 1989, 8:30 a.m.
through
Sunday, June 4, 1989, 12:00 noon

Organized and Sponsored by
Gazette International Networking Institute (G.I.N.I.)
International Polio Network (IPN)
International Ventilator Users Network (I.V.U.N.)
4502 Maryland Avenue, St. Louis, MO 63108 U.S.A.
314/361-0475

WELCOME

The Board of Directors and the Planning Committee welcome you. Our goal is to provide individuals with a disability and health professionals an opportunity to share information and to solve problems. We anticipate another very special meeting typical of the previous G.I.N.I. Conferences. We are glad you are here.

GAZETTE INTERNATIONAL NETWORKING INSTITUTE (G.I.N.I.)

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Max Starkloff
Joseph S. von Kaenel
Martin Wice, M.D.

AGENDA

Wednesday, May 31, 1989 INDEPENDENT LIVING WORLDWIDE

Ballroom, Third Floor

7:30 a.m.—8:30 a.m.
Continental Breakfast

8:30 a.m.—8:40 a.m.
Welcome
Joan Headley, B.S., M.S.
John L. Quigley, Jr., D. Min.
Jack Keane, Special Assistant to
Vincent C. Schoemehl, Jr., Mayor of St. Louis

"Impact of National Policy on Independent Living: International Case Studies"

MODERATOR: John L. Quigley, Jr., D. Min.

8:40 a.m.—8:50 a.m.
"A Status Report"
Judy Heumann

8:50 a.m.—9:25 a.m.
Case 1: *Disabled from Birth or Early Childhood*
Trevor Boyle; Zhang Li; Adolf Ratzka, Ph.D.

9:25 a.m.—10:00 a.m.
Case 2: *Disabled Later in Life*
Uwe Frehse; Robert J. Ronald, S.J.; John A. Micallef

10:00 a.m.—10:30 a.m.
Break

10:30 a.m.—11:05 a.m.
Case 3: *Secondary Disability*
Laurie Alsop; Holger Kallehauge; Judy Heumann;
Max Starkloff

11:05 a.m.—11:35 a.m.
"Overlapping Concerns: Aging, ADA, etc."
Mary Jane Owen, M.S.W.; Jim deJong; Ed Roberts

11:35 a.m.—11:45 a.m.
Closing Remarks

12:15 p.m.
Lunch

"What Really Limits Us? — Elevating Everyone's Expectations"

MODERATOR: Richard Goodwin

1:30 p.m.—2:45 p.m.
"Disability as a Social Role"
Richard Goodwin

Discussants: Speed Davis; Jim deJong; Cyndi Jones;
Carol Rowse; August Rüggeberg, Ph.D.; Max Starkloff

2:45 p.m.—3:15 p.m.
Break

3:15 p.m.—4:00 p.m.
Small discussion groups
Mark Twain, Ulysses S. Grant, Robert E. Lee,
Pierre Laclède

4:00 p.m.—4:45 p.m.
Summaries from discussion groups

5:00 p.m.—6:30 p.m.
DPI & Independent Living Meeting
South Lounge

6:30 p.m.
Dinner

Thursday, June 1, 1989 THE LATE EFFECTS OF POLIO

Ballroom, Third Floor

7:30 a.m.—8:30 a.m.
Continental Breakfast

8:30 a.m.—9:00 a.m.
"International Progress Reports:
Networking"

Joan Headley, B.S., M.S.; Audrey King, M.A.;
Rev. Robert J. Ronald, S.J.; Gertrud Weis

9:00 a.m.—10:15 a.m.
"International Progress Reports: Research"

MODERATOR: Roberta Simon, R.N.

Ruth Bell, D.N.Sc.; Carl A. Coelho, Ph.D.; D. Armin
Fischer, M.D.; Raymond Roos, M.D.; Jessica Scheer,
Ph.D.; Daria A. Trojan, M.D.; Anthony J. Windebank, M.D.

10:15 a.m.—10:45 a.m.
Break

10:45 a.m.—11:45 a.m.
"International Progress Reports: Research"
(continued)

James C. Agre, M.D., Ph.D.; Michael Fillyaw, M.S., P.T.;
Patricia Gilchrist, P.T.; Richard Owen, M.D.

12:15 p.m.
Lunch

1:30 p.m.—1:40 p.m.
"Bridging the Gap between Research
& Clinical Applications"

Frederick Maynard, M.D.

1:40 p.m.—2:45 p.m.
"Prescription for Fatigue"

MODERATOR: Martin B. Wice, M.D.

Jane Dummer; Richard Owen, M.D.; William Waring, M.D.

2:45 p.m.—3:15 p.m.
Break

(continued on page 2)

AGENDA (continued from page 1)

3:15 p.m.—3:35 p.m.

"Prescription for Underventilation"

MODERATOR: Marny Eulberg, M.D.
Geoffrey T. Spencer, FFARCS

3:35 p.m.—4:45 p.m.

"Prescription for Weakness"

MODERATOR: Marny Eulberg, M.D.
James C. Agre, M.D.; Daria A. Trojan, M.D.;
Jacquelin Perry, M.D.

6:30 p.m.

Dinner

8:15 p.m.

Support Dogs for the Handicapped, Inc. —
St. Louis

Friday, June 2, 1989

THE LATE EFFECTS OF POLIO

Ballroom, Third Floor

7:30 a.m.—8:30 a.m.

Continental Breakfast

8:30 a.m.—9:40 a.m.

"Prescription for Pain"

MODERATOR: Frederick Maynard, M.D.
Thomas P. Anderson, M.D.; Ernest W. Johnson, M.D.;
Renah Shnaider

9:40 a.m.—10:00 a.m.

Break

10:00 a.m.—11:30 a.m.

"Suggestions for Exercise and Energy Conservation"

MODERATOR: Nancy Caverly, O.T.R.
Glenn Ham-Rosebrock, C.O.; Jacquelin Perry, M.D.;
Shirley Sahrman, Ph.D., P.T.; Richard Owen, M.D.

11:30 a.m.—11:45 a.m.

"Being an Active Participant in Your Health Care"

Dorothy Woods Smith, R.N.

"The Body AND the Mind"

Jack Genskow, Ph.D.

12:15 p.m.

Lunch

1:30 p.m.—2:30 p.m.

"Psychological Adjustment: Professional Point of View"

MODERATOR: Stanley Yarnell, M.D.
Ruth Bell, D.N.Sc.; Lauro Halstead, M.D.; Frederick
Maynard, M.D.; Renah Shnaider

2:30 p.m.—3:00 p.m.

Break

3:00 p.m.—3:30 p.m.

"Psychological Adjustment: Personal Point of View"

3:30 p.m.—4:45 p.m.

Discussion Groups:

- 1 — Soulard Seminar
- 2 — Mark Twain
- 3 — South Lounge
- 4 — Ulysses S. Grant
- 5 — Robert E. Lee
- 6 — Eugene Field
- 7 — Auguste Chouteau
- 8 — James Eads
- 9 — Boulevard A
- 10 — Boulevard B
- 11 — Pierre Laclede
- 12 — Ballroom West
- 13 — Ballroom Center
- 14 — Ballroom East
- 15 — Ragtime I (Second Floor)

5:00 p.m.—6:30 p.m.

Clinic Personnel Meeting
Ulysses S. Grant

5:00 p.m.—6:30 p.m.

DPI & Independent Living Meeting
South Lounge

Friday Night in St. Louis

Saturday, June 3, 1989

ETHICAL CHALLENGES AND SOCIAL POLICY: DISABILITY & AGING

Ballroom, Third Floor

MODERATOR: Lawrence C. Becker, Ph.D.
Discussants: Ingolf Osterwitz, Ph.D.;
Jack Genskow, Ph.D.; August Rüggeberg, Ph.D.

8:30 a.m.—9:45 a.m.

"Ethical Theory, Medical Care, and Life and Death Decisions"

Lawrence C. Becker, Ph.D.; Daniel Wikler, Ph.D., M.D.

9:45 a.m.—10:15 a.m.

Break

10:15 a.m.—11:45 a.m.

"Mutual Decision-Making in Life and Death Situations"

- "Choices for ALS Patients"
August Alba, M.D.
- "Ventilators & Muscular Dystrophy"
Agatha Colbert, M.D.
- "Choice to End Life"
Frederick Maynard, M.D.

12:15 p.m.

Lunch

12:30 p.m.—2:45 p.m.
Catholic Commission for the Handicapped
Ragtime I, Second Floor

HOME MECHANICAL VENTILATION WORKSHOP

Boulevard A & B

"Summaries by the Experts"

MODERATOR: Oscar A. Schwartz, M.D.

- 1:30 p.m.—1:50 p.m.
"Historical Perspectives"
Gini Laurie; Joseph Kaufert, Ph.D.
- 1:50 p.m.—2:00 p.m.
"Anesthesia in Severe Disability"
Geoffrey T. Spencer, FFARCS
- 2:00 p.m.—2:10 p.m.
"Tracheostomy Alternatives—SCI"
Susan Sortor, R.R.T.
- 2:10 p.m.—2:20 p.m.
"Sleep-Related Breathing Abnormalities"
Oscar A. Schwartz, M.D.
- 2:20 p.m.—2:30 p.m.
"The Changing Ventilation Needs of
Polio Survivors"
Redento Ferranti, M.D.
- 2:30 p.m.—2:40 p.m.
"Swallowing Management"
Carl A. Coelho, Ph.D.
- 2:40 p.m.—3:00 p.m.
Questions and Answers
- 3:00 p.m.—4:00 p.m.
Discussion Groups
"Muscular Dystrophy — Informed Choices"
Agatha P. Colbert, M.D.
Pierre Laclede
"Home Ventilator Maintenance"
Jerry Daniel, Geoffrey Waters
Robert E. Lee
"Travel with Ventilators"
Jack Genskow, Ph.D.; Adolf Ratzka, Ph.D.
Ulysses S. Grant
"Home Ventilation in Children and Adolescents"
Allen I. Goldberg, M.D., Virginia Nelson, M.D.
South Lounge

4:00 p.m.—5:30 p.m.

"New Face Masks and CPAPs & Glossopharyngeal Breathing"

Boulevard A & B

MODERATOR: Augusta Alba, M.D.

Bud Blitzer; Dano S. Carbone; Pat Hanzke; Adolf Ratzka,
Ph.D.; Oscar Schwartz, M.D.; Sue Sortor, R.R.T.; Geoffrey
Waters

6:00 p.m.

Roman Catholic Mass
Ragtime I, Second Floor

6:30 p.m.
Cash Bar
Ballroom Foyer, Third Floor

7:30 p.m.
Banquet
Ballroom, Third Floor
Karen Foss, KSDK-TV, Channel 5
Mickie McGraw, A.T.R., B.F.A., Past President of the
G.I.N.I. Board
John L. Quigley, Jr., D. Min., President of the
G.I.N.I. Board

9:30 p.m.—11:30 p.m.
Music

Sunday, June 4, 1989

SPECIAL INTEREST WORKSHOPS

7:30 a.m.—8:30 a.m.
Registration and Continental Breakfast
Ballroom Foyer

7:30 a.m.—8:30 a.m.
Support Group Leaders' Meeting
Ragtime I, Second Floor

8:30 a.m.—9:30 a.m.
Session I

9:45 a.m.—10:45 a.m.
Session II

11:00 a.m.—12:00 a.m.
Session III

TAMING TECHNOLOGY: OVERVIEW OF DEVICES FOR SPECIAL NEEDS

Aimee J. Luebben, M.S., O.T.

This presentation will highlight the latest commercially available technological devices for special needs, show trends and products in the research and development stages, and discuss low cost technological options.

Sessions I, III: *Ulysses S. Grant*

RECREATIONAL ADAPTATIONS

Gordon Packer, Ph.D., P.Eng.

Slide and tape presentation of adaptive devices for recreational use.

Sessions I, III: *Robert E. Lee*

TECHNOLOGY: INDEPENDENT LIVING AND WORK

Keith Sofka

Information exchange and problem solving about technology and access to work, home, and recreation.

Session II, III: *Auguste Chouteau*

SO...YOUR HOME DOESN'T FIT ANYMORE?

Rae Duncan-Lyle

Suggestions for making your home accessible, slides of design options, working with contractors, and possible funding sources in your community. Questions wanted — there is no such thing as a silly question.

Sessions I, III: *Pierre Laclede*

(continued on page 4)

SPECIAL INTEREST WORKSHOPS

(continued from page 3)

VOLUNTEER SERVICE BANK

Marilyn Probe, Ed.D.

Volunteers over 60 receive state insured credit through the Missouri Division of Aging for giving respite care to persons with a disability and elderly individuals. Younger volunteers can donate their credits to someone over 60.

Session II: South Lounge

ATTENDANT CARE SCHEMES IN WEST GERMANY

Ingolf Osterwitz, Ph.D.

A presentation of the different community-based services available for individuals with a severe disability in West Germany.

Session I: South Lounge

FINANCIAL PLANNING TO PRESERVE ENTITLEMENTS

**Gerald J. Zafft
Ann C. Sheehan**

Financial and legal advice for persons with disabilities and their families to avoid losing government benefits.

Sessions I, II: Eugene Field

LEGAL RIGHTS AND LEGAL ISSUES

Sidney M. Wolinsky

A presentation on legal rights and issues affecting individuals with a disability and independent living such as the right to an education, airline travel, etc.

Session I: James Eads

THE SUPPORT GROUP LEADER'S ROLE AS A PEER COUNSELOR

**Ingolf Osterwitz, Ph.D.
Judge Anderson, III, M.S., M.S.W.
Duane Gruis, M.S.**

Techniques and strategies for helping peers cope with familiar problems.

Session III: Eugene Field

COMMUNITY RESOURCES FOR SUPPORT GROUPS: WHAT HAS (OR HAS NOT) WORKED

**Roberta Simon, R.N.
Greg Larbes
Caroleanne Green
Barbara Miller**

Presentations by group leaders to share their successes at using community resources to complement a support group.

Session II: Boulevard B

LIVING ALONE

Susan Armbrecht

A short personal history relating management of attendants and self. Description of a support system with friends, relatives, and community services while trying not to go crazy when life falls apart.

Session II: Mark Twain

COPING SUCCESSFULLY WITH POLIO'S LATE EFFECTS

Sunny Roller

What are some common post-polio problems? What are often typical and immediate reactions to these problems? How does an individual integrate these unwelcome physical changes? These questions are sensitively discussed in the videotape, "Coping Successfully with Polio's Late Effects," which will be shown at this session. Participants will view the videotape and have an opportunity to share their personal responses to the tape, to their own post-polio experience, and discuss how that experience can become an opportunity to help others.

Sessions I, II: Boulevard A

LOWER EXTREMITY ANATOMICAL NEEDS VS. BRACING COMPONENTS

Glenn Ham-Rosebrock, C.O.

A discussion of the challenge of mechanically duplicating what is anatomically compromised as it relates to the individual's needs.

Sessions II, III: James Eads

TAPPING INTO OUR HIDDEN POWER

Paul J. Rau

Restructuring the "overcome philosophy" in a self-help process which closely resembles the original alliance between young patient/physician/parents. Many polio survivors have made no changes in the overcome philosophy which was learned as children at the acute onset stage.

Session II: Ulysses S. Grant

CURRENT THESIS REPORTS ON THE LATE EFFECTS OF POLIO

Barbara R. Buchanan

"Physical, Emotional, and Social Adaptation to the Late Effects of Poliomyelitis"

Ann H. Lewis, M.N., R.N.C.

"Life Histories of Polio Survivors Residing in a Long-term Care Community: A Pilot Study"

Session I: Boulevard B

HOW TO LIVE HAPPILY EVER AFTER SANS PPS

Mari Zigmund

A video to encourage other polio people to think more carefully about nutrition. This is in no way to be contrary to the excellent care done and being done by research in the medical field.

Session III: South Lounge

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Information ...

Registration

The registration desk is located on the third floor in the Ballroom Foyer on the rail. Participants may register on Tuesday, May 30 from 5:30 p.m. to 8:30 p.m., on Wednesday, May 31 from 7:30 a.m. to 5:30 p.m., on Thursday and Friday, June 1 & 2, from 7:30 a.m. to 2:00 p.m., Saturday, June 3 from 7:30 a.m. to 6:00 p.m., and on Sunday, June 4 from 7:30 a.m. to 8:30 a.m.

Medical Assistance

SSM Rehabilitation Institute has arranged for a physician to be on call 24 hours a day. If you need emergency medical assistance, call the hotel operator. When speaking with the operator, be sure to give your location and the phone number where you can be reached.

Procedures for Sessions

To facilitate discussion following the presentations in the Ballroom, we request that all questions be made in writing. Materials for that purpose will be located on the tables and will be collected and given to the moderator.

Some written material is provided in the Conference program. Participants are encouraged to review it in advance of the respective session. Other information will be made available during specific sessions.

No smoking will be permitted during the sessions. Smoking is permitted in the Foyer.

Messages

A message board is located in the Ballroom Foyer.

Telephone

Public telephones are located in the Ballroom Foyer next to the bar and the restrooms. The telephone at the Registration Desk is for Conference business only.

Meals

Catering has requested that we vacate the Ballroom as quickly as possible after the morning sessions so they can set up for the 12:15 p.m. lunch.

The menus for all Conference meals are posted on the message board in the Ballroom Foyer. Additional meal tickets must be purchased 48 hours in advance and may be obtained at the Registration Desk. Meal tickets must be presented to the servers.

Smoking is not permitted during meals.

Friday Night

Information concerning places to go and things to do on Friday night can be obtained at the table in front of the bar in the Ballroom Foyer. This service is provided by the Greater St. Louis Post-Polio Support Group.

For your safety we ask that you remember that St. Louis is like any large city and that you take necessary precautions. When leaving the hotel, it is better to go in a group.

Abilities Expo-Midwest

Abilities Expo-Midwest will be held at the Cervantes Convention Center on Friday, June 2 and Saturday, June 3 from 11:00 a.m. to 6:00 p.m. and on Sunday, June 4 from 11:00 a.m. to 5:00 p.m. The Convention Center is directly across Seventh Street from the Sheraton St. Louis, but the accessible entrance is on Convention Plaza (the south side of the Convention Center). Admission is free.

Wednesday, May 31, 1989

"Impact of National Policy on Independent Living: International Case Studies"

Case 1

DISABLED FROM BIRTH OR EARLY CHILDHOOD.
Secondary education completed. Very intelligent with excellent grades.

Female. 18 years old. CP. Ambulatory. Used braces initially. Presently uses cane. Good use of hands. Mild spasticity. Speech difficult to understand. Attended special school for two years. Subsequent education at regular school.

Case 2

DISABLED LATER IN LIFE
Education completed.
Career stabilized.

Male. 32 years old. Mathematics teacher of 15-17 year old students. Married. Wife works as secretary. No children. C5-6. Result of automobile crash. Recently returned home from initial treatment. Two-story home inaccessible. School building on one level located 4 miles from home.

Case 3

SECONDARY DISABILITY
Successful career.
Unaware of world of disability and availability of services.

Male. 43 years old. Married. Wife recently returned to nursing. Three children (age 20,17,15). Owns four automobile dealerships in two cities. Polio paralyzed both legs at age nine. Recovered function with slight limp. Avid jogger. Age 41, experienced pain, weakness, fatigue. Misdiagnosed as Guillain-Barre. Three months ago, diagnosed as late effects of polio by a polio clinic. Prescription of wheelchair caused depression. Now plans to retire on government disability.

Fall 1

BEHINDERUNG SEIT GEBURT ODER FRÜHER KINDHEIT

Höhere Schulbildung abgeschlossen.
Sehr intelligent, mit ausgezeichneten Noten

Weiblich, 18 Jahre alt. Zerebralparalyse CP! (Spastiker)
Gehbehinderung.

Anfangs mit Gehapparat, benutzt jetzt einen Stock.
Gute Funktion der Hände. Milde spastische Lähmung.
Sprach-Behinderung, schwer verständlich!
Besuchte 2 Jahre lang eine Sonderschule.
Anschließend Ausbildung in regulärer Schule.

Fall 2

BEHINDERUNG IM SPÄTEREN LEBEN

Ausbildung abgeschlossen.
Berufliche Laufbahn stabil.

Männlich. 32 Jahre alt.
Mathematiklehrer von 15 bis 17-jährigen Schülern.
Verheiratet. Frau arbeitet als Sekretärin.
Keine Kinder.
Querschnittslähmung C5/C6 nach Autounfall.
Kürzlich aus dem Krankenhaus nach Hause entlassen.
Eigenes, zweistöckiges Wohnhaus - unzugänglich.
Ebenerdiges Schulgebäude 4 Meilen (ca. 6,4 km) von Wohnhaus
entfernt.

Fall 3

SEKUNDÄRE BEHINDERUNG

Erfolgreiches Berufsleben.
Kein spezifisches Bewußtsein über "die Welt der Behinderten".
und der verfügbaren Dienstleistungen.

Männlich, 43 Jahre alt.
Verheiratet. Ehefrau arbeitet seit kurzem wieder als
Krankenschwester.
Drei Kinder (20, 17, 15 Jahre alt).
Besitzt vier Automobilgeschäfte in zwei Städten.
Mit 9 Jahren Polio-Lähmung in beiden Beinen.
Beinfunktion wiedergewonnen, jedoch leichtes Hinken.
Eifriger Jockey.
Auftreten von Schmerzen, Schwäche, Müdigkeit im 42. Lebensjahr.
Falsch diagnostiziert als Landry-Guillain-Barré-Syndrom*.
Vor 3 Monaten in Polio-Klinik als Spätfolgen der Poliomyelitis
diagnostiziert.
Verordnung eines Rollstuhls verursachte Depression.
Plant jetzt Ruhestand mit staatlicher Schwerbehinderten-Rente.

* aufsteigende Lähmung;

Caso primero.

Discapacitado desde el nacimiento o la niñez.
Terminó la educación secundaria (el bachillerato).
Muy inteligente, con notas excelentes.

Mujer. 18 años de edad. Perlesía cerebral.
Ambulatoria. Inicialmente usó tablillas.
Buen uso de las manos. Espasticidad moderada.
Es difícil entenderla por la articulación.
Estudió en un colegio especial por dos años.
Después en colegios normales.

Caso segundo.

Discapacitado de adulto.
Terminó la educación.
Tiene éxito en su carrera.

Hombre. 32 años de edad.
Profesor de matemáticas de estudiantes de 15-17 años.
Casado. La esposa trabaja como secretaria.
No tiene hijo. C5-6.
Resulta de un choque automovilístico.
Recientemente volvió a casa de su tratamiento inicial.
Casa de dos pisos inaccesible.
Colegio de un solo piso a 4 millas de la casa.

Caso tercero.

Discapacidad secundaria.
Tiene éxito en su carrera.
Ignorante del mundo de las discapacidades y de los servicios disponibles.

Hombre. 43 años de edad. Casado.
Esposa volvió a ser enfermera recientemente.
Tres niños (de 20, 17, y 15 años de edad).
Tiene cuatro empresas de vender autos en dos ciudades.
La polio le paralizó las piernas a la edad de 9 años.
Recuperó funcionamiento con una cojera ligera.
Le gusta correr (para hacer ejercicio).
A la edad de 41 años experimentó dolor, debilidad, y fatiga.
Maldagnosticado como Guillain-Barré.
Hace tres meses, diagnosticado en una clínica de la polio con efectos tardíos de la polio.
Receta de una silla de ruedas le deprimió.
Ahora piensa jubilarse y recibir fondos federales por su discapacidad.

Wednesday, May 31, 1989

"What Really Limits Us? – Elevating Everyone's Expectations"

Richard Goodwin, member of the G.I.N.I. Board of Directors, is the Executive Director of IMPACT, Inc., Alton, IL. Mr. Goodwin wrote the following as part of a position paper for IMPACT.

"Disability as a Social Role"

The history of people with a disability in America has never been studied or written about in any methodical, comprehensive fashion. There have been writings published regarding specific disabilities in history, and specific approaches such as people with a disability in literature, but no comprehensive writing regarding what it means to become disabled in America has ever been published.

It is difficult to extrapolate what actually limits people with disabilities given the dearth of an historical perspective. However, the independent living movement, with which IMPACT is associated, has focused on disability as a role in society and how the expectations associated with that role are terribly restrictive, patronizing, and essentially offer little hope of living a full and productive life.

A social role simply defined is a grouping of expectations. Any role that you can think of, whether son, mother, doctor, friend, or second baseman, consists of numerous expectations. The disability role is fraught with restrictive, negative expectations which lead a person to believe that life must be miserable and extremely limiting. Some of the expectations associated with the disability role include the following:

- a. the expectation that you sick,
- b. the expectation that you need to be taken care of an should not live alone,
- c. the expectation that you cannot work,
- d. the expectation that it is in your best interest to exclude you from your age and community peers in the educational process,
- e. the expectation that you do not have an inalienable human right to fully participate in your community,
- f. the expectation that you will be perpetually depressed about your lot in life,
- g. the expectation that your travel needs will be vastly different from the general public,
- h. the expectation that you are asexual.

These expectations are reinforced by American policies and laws which provide vast amounts of funding to support keeping us in the dependent, low status, separated, un-American, archaic, patronizing disability role. The disability role is, of course, an ascribed role that we do not choose to enter. However, society makes it very difficult to break out of the disabili-

(continued on page 15)

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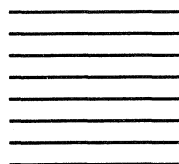
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"What Really Limits Us?"

(continued from page 13)

ity role because often the power of American law requires that we be limited in our options. Those who do manage to rise above the disability role are thought to be brave and heroic, when in reality they are simply seeking to live a normal American life in the face of discriminatory, restrictive policies and laws.

The disability role is, of course, the logical extension of the archaic notions and prejudices which Americans have come to accept as facts regarding people with disabilities. Most Americans never interact with persons with a disability on a peer level, and are not even likely to be in the mere co-presence of persons with a disability due to the fact that historically persons with a disability have been kept out of the mainstream of American life. Even today it remains the exception for a child with a severe disability to be educated with his or her age and community peers. No wonder Americans carry with them archaic notions regarding what it means to have a disability.

Our laws, regulations, and policies essentially preclude face to face interaction between disabled and non-disabled children, and yesterday's children are today's legislators, personnel directors, teachers, and bureaucrats. It is important to highlight the fact that those of us who become disabled, and those of us who become parents of children with a disability, are fraught with the archaic notions we have tacitly accepted as fact. There is nothing more important than educating persons with disabilities and parents that a disability can be effectively managed, and people must raise their expectations as to what it is possible to accomplish as a person with a disability. Accepting society's ascribed disability role is equivalent to compliance

with a life of limited options, depression, exclusion, and isolation.

People with disabilities achieve less, earn less money, have less education, more poverty, less health care, less transportation options, enjoy social/recreational activities less, are less politically active, and receive prejudicial treatment routinely. The disability role, when perpetuated at the community level results in restrictive policies and laws which limit fully integrated community participation of people with disabilities in every social context and every type of disability is affected, whether physical, mental, or sensory. Additionally, when disability occurs to an individual acceptance of the disability role as your lot in life correlates with low achievement, low self-esteem, and inability to manage and cope with life with a disability.

Promoting full community participation of people with disabilities is an issue involving social, political, social/psychological, moral, economic, and legal issues. Strategies for social inclusion of people with disabilities must effectively influence a broad spectrum of societal entities.

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The Late Effects of Polio: An Overview

Gini Laurie, St. Louis, MO

Polio, the dread disease of the 1950s, was virtually eliminated in the United States by the vaccines and almost forgotten except by the survivors. The majority of those survivors, with zest and determination, achieved maximum rehabilitation and lived full and productive lives in their communities. In the past several years, however, as they have grown older, some have begun to experience the late effects of polio - pain, weakness, fatigue, and sleep and breathing problems.

The Center for Disease Control estimates that there are between 200,000 and 250,000 people in the United States who have residual paralysis resulting from polio. Studies by the Mayo Clinic indicate only about 25% of the survivors may experience the late effects.

The most commonly reported symptoms of the late effects are:

- unaccustomed fatigue - either muscle fatigue or generalized body fatigue
- weakness in muscle - both those originally affected and those unaffected
- pain in muscles or joints
- sleep problems
- breathing difficulties
- swallowing problems

Unfortunately, the late effects of polio are still not well known among many physicians and they are difficult to distinguish from arthritis and other degenerative disorders of muscles, ligaments, and joints. Survivors who develop these new problems may be told "It is all in your head," given

inappropriate prescriptions, or sent for expensive referrals. A frequent complaint is that their physicians do not appear to listen to them.

It is not difficult for polio survivors or physicians to become knowledgeable about the late effects. International Polio Network (IPN) through its conferences, workshops, and publications provides information and through its network of support groups provides people.

As a first step in prevention and treatment, polio survivors should undergo a general medical evaluation so one has a baseline from which to judge whether and to what extent one is experiencing the late effects. IPN, by publishing a directory of clinics and resource persons, can assist in finding an open-minded and understanding physician.

Early recognition, corrective procedures, and increased use of assistive devices can do much to alleviate pain and distress. A new brace may be needed, perhaps current crutches are damaging the arms or wrists, and a wheelchair should be used for shopping or traveling. Perhaps the arms are wearing out from propelling a manual wheelchair and a motor should be added or a change made to one of the new three-wheeled motorized chairs.

Most polio survivors have been pushing beyond their strength, trying too hard, refusing to give in or acknowledge weakness. They have been overcompensating, over-achieving and, possibly, overeating.

It's time for a long, honest look at one's lifestyle. It's time to think about moderation, conservation, and common sense. Expert polio physicians at the international

The Late Effects of Polio

(continued from page 16)

polio conferences make the following recommendations:

- don't overexercise; try swimming
- don't overuse
- rest when one is tired - stop for a 15- to 30-minute rest in midafternoon
- watch weight gains
- don't smoke
- don't overindulge in alcohol
- avoid narcotics

- listen to one's own body
- pace one's self; slow down

Of course, these recommendations are not easy to follow. But they will be much easier if one has the support and understanding of other polio survivors who are facing the same changes. There are more than 250 self-help polio support groups all around the world. They are an invaluable source of information about local physicians, therapists, braced makers, and a helping hand with adaptation to change.

One can cope with the late effects of polio by using common sense, staying informed, and sharing with other polio survivors.

SPEAK UP AND BE HEARD

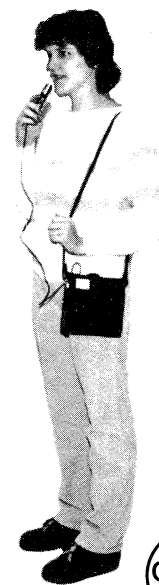


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The doctors, nurses, therapists and other specialists of St. John's Mercy Rehabilitation Center are well-trained and experienced in the treatment and rehabilitation of:

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Established in 1963, St. John's Mercy Rehabilitation Center was the first comprehensive inpatient rehabilitation program in St. Louis to earn accreditation from the Commission on Accreditation of Rehabilitation Facilities (CARF). CARF's certification confirms St. John's highest standards of treatment, follow-up, facilities and technical support.

It also attests to the kind of rehabilitation we believe every patient deserves—rehabilitation that helps each one reach for the most, both physically and emotionally.



St. John's Mercy Rehabilitation Center

at St. John's Mercy Medical Center
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(314) 569-6040

Underventilation

Everyone's lungs change and deteriorate with age, and polio survivors, with their already limited respiratory reserve, may reach a point at which intermittent mechanical ventilation becomes necessary.

Symptoms of underventilation are:

- trunk weakness, often including scoliosis,
- loss of energy and a tendency to fall asleep easily during the day,
- general weakness and fatigue often affecting muscles not previously recognized as being weakened by polio,
- a feeling that the air in the room is in some way bad,
- claustrophobia,
- loss of mental concentration and reduced work capacity, often mistakenly attributed to lack of oxygen to the brain (treatment by oxygen therapy alone may be dangerous and can lead to acute respiratory arrest),
- sleep disturbances taking various forms, including difficulty in getting to sleep, awakening during the night with nightmares, awakening during the night feeling short of breath, waking up feeling unrefreshed or with a headache,
- frequent chest infections with difficulty in shaking off coughs or colds.

Not everyone has all the symptoms listed above, and some of the symptoms can be caused by other things, but anyone with more than 2 or 3 should be evaluated by a pulmonary specialist.

Signs of underventilation include quiet speech with fewer words per breath when speaking, difficulty in speaking for more than a short time, a reduction in breath holding time, and the obvious use of unusual muscles when breathing such as head, neck, shoulders, or arms. Cyanosis (blueness of the lips and fingernails) is a very late sign of underventilation, and this absence should not be regarded as sufficient reassurance that underventilation is not occurring.

Forced vital capacity should be measured in supine, sitting, and standing positions, and a measurement showing 400-600 ccs indicates serious underventilation. Unfortunately, in polio survivors with weak muscles and low vital capacities, formal lung function tests can be misleading. Arterial blood gas studies can often be normal during wakefulness by day, only becoming abnormal during sleep. Underventilation among polio survivors occurs primarily during sleep, and a sleep study is often helpful.

Fortunately, underventilation can be treated successfully.



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What is the International Polio Network?

The International Polio Network (IPN) is the world center of information on polio and the late effects of polio. IPN was formally established in 1985 by Gazette International Networking Institute (G.I.N.I.) to link polio survivors and to coordinate post-polio support groups.

G.I.N.I. was founded in 1958 by Gini Laurie to publish an international journal, *Rehabilitation Gazette*, written by and for persons disabled by polio.

The *Rehabilitation Gazette* has always maintained a network of polio survivors. Therefore, in 1979, it was the first to recognize the increasing numbers of polio survivors reporting new symptoms of pain, fatigue, weakness, and breathing difficulties.

Today, IPN directed by Joan Headley:

- Publishes the Polio Network News, a quarterly newsletter.
- Compiles and publishes the Post-Polio Directory of 250 support groups, 60 clinics, and 100 health professionals.
- Organizes support group leaders' workshops and resources 250 support groups.
- Organizes biennial international polio and independent living conferences for polio survivors and health professionals and publishes proceedings of these conferences.
- Publishes the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. (Available from IPN for \$6.75.)

Membership in IPN is \$8 a year for polio survivors and \$15 for health professionals. Members receive the *Polio Network News* and the *Post-Polio Directory*.

Gazette International Networking Institute's other activities are, also, centered around "reaching, informing, and dignifying people with disabilities throughout the world." G.I.N.I. publishes the *Rehabilitation Gazette*, the *International Ventilators Users Network* newsletter, and a handbook discussing *Ventilators and Muscular Dystrophy*.

G.I.N.I. is a non-profit 501(3)(c) organization and donations are tax-deductible. Many friends and supporters of G.I.N.I. regularly donate to the many facets of the work of Gini Laurie and G.I.N.I.

G.I.N.I. and IPN thrive and survive on the networking of polio survivors everywhere. The information shared by one benefits all. In short, as a polio survivor, you need IPN and IPN needs you.

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- Family Adjustment
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- Education and Employment
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May 31 - June 4, 1989

"Rehabilitation Into Independent Living" the 30th Anniversary Edition of the Rehabilitation Gazette (1988, Vol. 29, Nos. 1 & 2) edited by Laurie, Headley, and Mudrovic. Contains forty retrospective and introspective articles by individuals with a disability explaining how they got "here from there."

\$15.95 postpaid

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors edited by Laurie, Maynard, Fischer, and Raymond. A 48-page booklet in a dictionary format that contains information about the clinical problems associated with the late effects of polio based on the experiences of physicians and polio survivors.

\$6.75 postpaid

Ventilators & Muscular Dystrophy by Nancy C. Schock, M.A. and Agatha P. Colbert, M.D. Discusses the availability and increasing use of mechanical ventilation for persons with Duchenne muscular dystrophy (DMD) that is changing the prognosis for the life expectancy of the disease.

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Polio Network News & the Post-Polio Directory edited by Joan Headley. A quarterly newsletter with current information about the late effects of polio and disability-related topics. Directory lists clinics, health professionals, and support groups.

\$8.00-polio survivors / \$15.00-health professionals

I.V.U.N. News edited by Gini Laurie & Joan Headley. A bi-annual newsletter for ventilator assisted individuals and their families and health professionals providing a worldwide network.

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	<u>Audio Cassette</u>	<u>VHS ½" Video</u>
<u>Tape #1</u> - Impact of Natl. Policy on Independent Living: International Case Studies 2-Tape Session Date: 5-31-89 Time: 8:30 a.m. - 11:45 a.m.	_____	_____
<u>Tape #2</u> - What Really Limits Us? Elevating Everyone's Expectations 2-Tape Session Date: 5-31-89 Time: 1:30 p.m. - 4:45 p.m.	_____	_____
<u>Tape #3</u> - International Progress Reports: Networking and Research 2-Tape Session Date: 6-1-89 Time: 8:30 a.m. - 11:45 a.m.	_____	_____
<u>Tape #4</u> - Prescription for Fatigue, Underventilation, and Weakness 2-Tape Session Date: 6-1-89 Time: 1:30 - 4:45 p.m.	_____	_____
<u>Tape: #5</u> - Prescription for Pain, Exercise, and Energy Conservation 2-Tape Session Date: 6-2-89 Time - 8:30 a.m. - 11:30 a.m.	_____	_____
<u>Tape #6</u> - Psychological Adjustment: Several Points of View Including Yours 1-Tape Session Date: 6-2-89 Time: 1:30 p.m. - 3:30 p.m.	_____	_____
<u>Tape: #7</u> - Ethical Theory, Medical Care, & Life and Death Decisions 1-Tape Session Date: 6-3-89 Time: 8:30 a.m. - 9:30 a.m.	_____	_____
<u>Tape #8</u> - Mutual Decision-Making In Life & Death Situations 1-Tape Session Date: 6-3-89 Time: 10:00 a.m. - 11:45 p.m.	_____	_____

HOME MECHANICAL VENTILATION WORKSHOP

<u>Tape: #9</u> - Ventilation Problems & Solution of Anesthesia, Tracheostomies, Sleep and Swallowing-Related to Polio, S.C.I. 1-Tape Session Date: 6-3-89 Time: 1:30 p.m. - 3:00 p.m.	_____	_____
<u>Tape #10</u> - Muscular Dystrophy - Informed Choices 1-Tape Session Date: 6-3-89 Time: 3:00 - 4:00 p.m.	_____	_____
<u>Tape #11</u> - Home Ventilator Maintenance 1-Tape Session Date: 6-3-89 Time: 3:00 p.m. - 4:00 p.m.	_____	_____

	<u>Audio Cassette</u>	<u>VHS 1/2" Video</u>
<u>Tape #12</u> - Travel With Ventilators 1-Tape Session		
Date: 6-3-89 Time: 3:00 p.m. - 4:00 p.m.	_____	_____
<u>Tape #13</u> - Home Ventilation in Children & Adolescents 1-Tape Session		
Date: 6-3-89 Time: 3:00p.m. - 4:00 p.m.	_____	_____
<u>Tape #14</u> - Demonstrations of New Face Masks, Cpaps and Glossopharyngeal (Frog Breathing) 1-Tape Session		
Date: 6-3-89 Time: 4:00 p.m. - 5:30 p.m.	_____	_____

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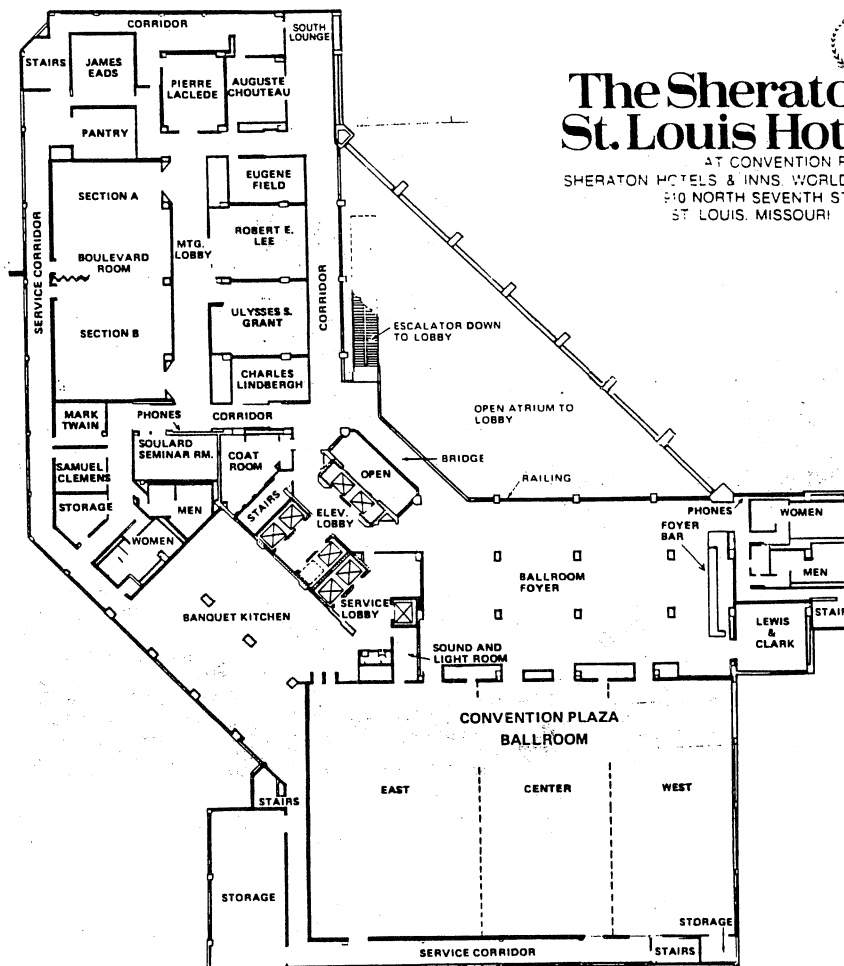
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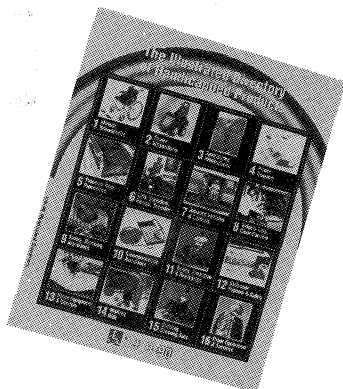


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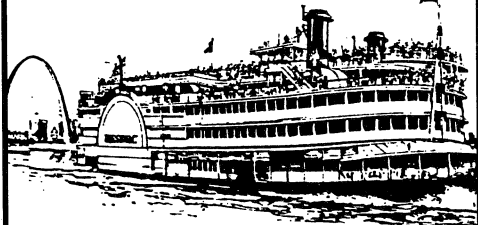
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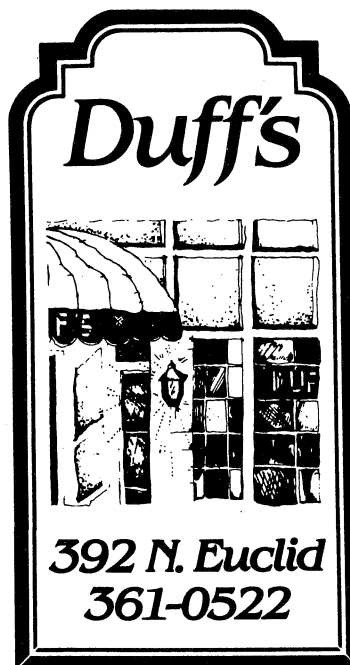


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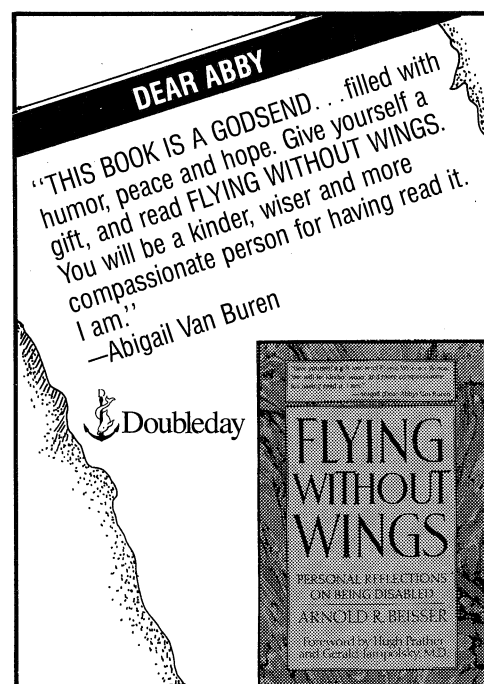
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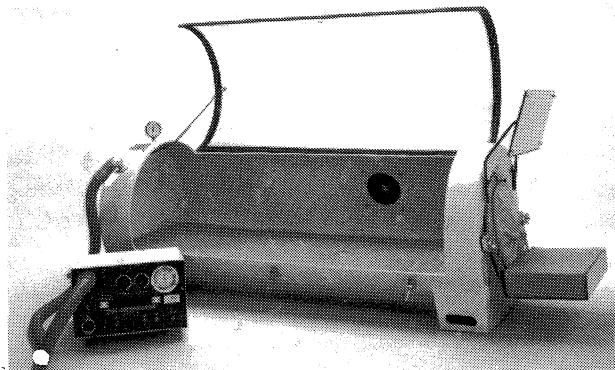
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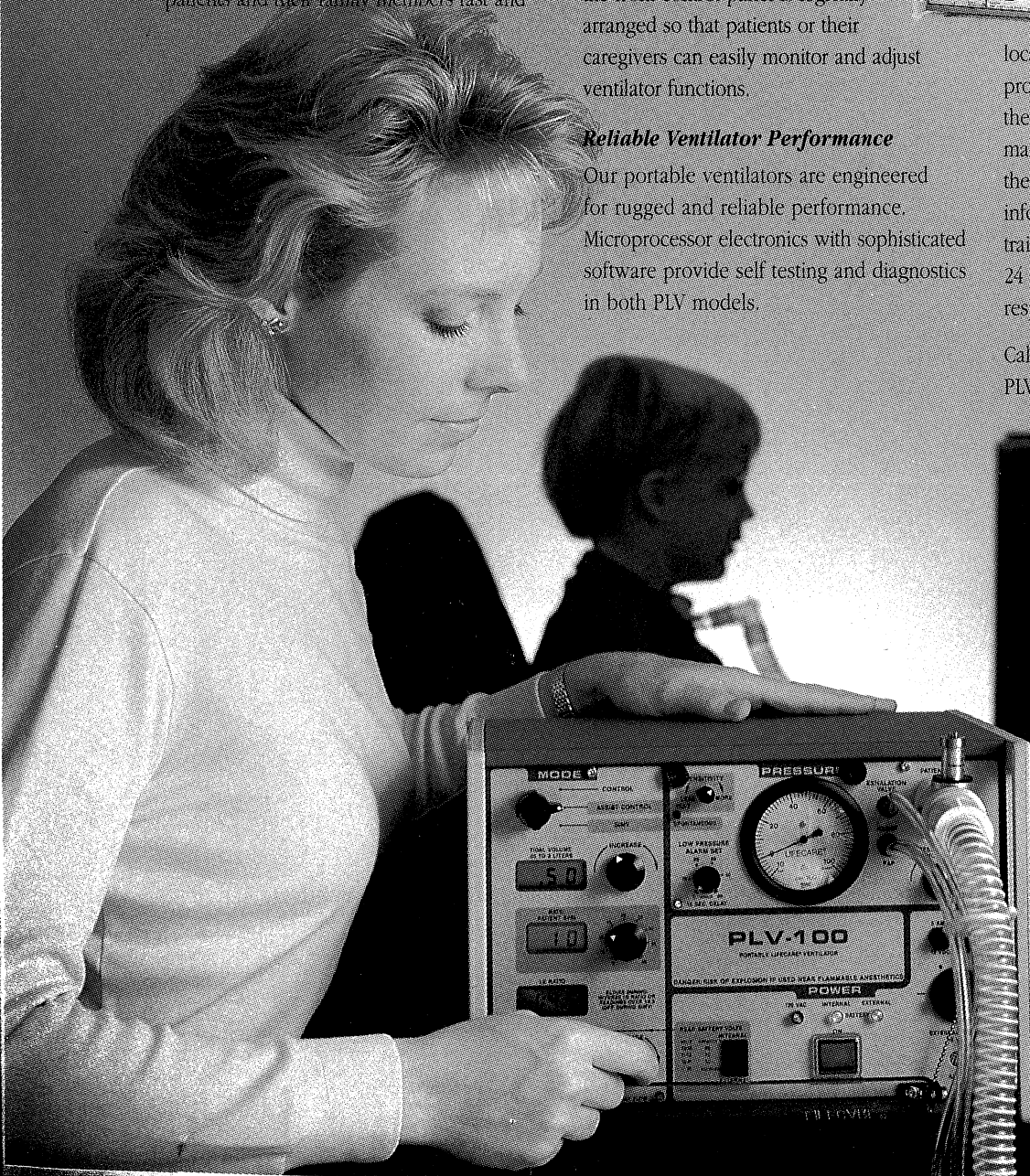
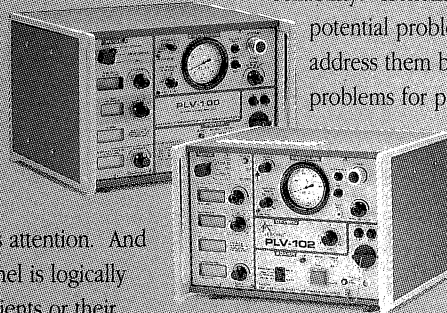
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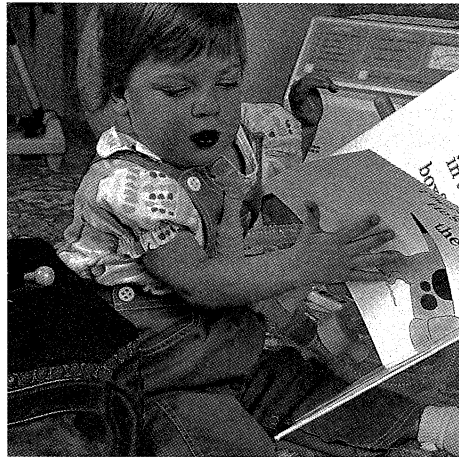
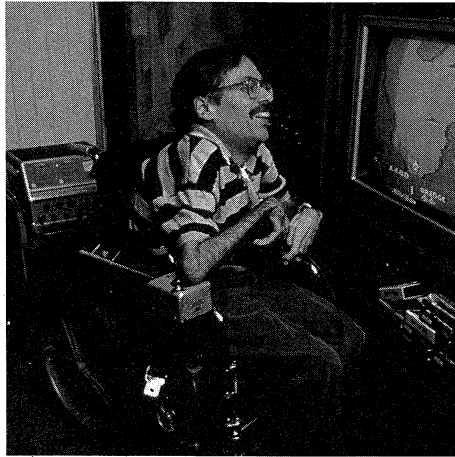
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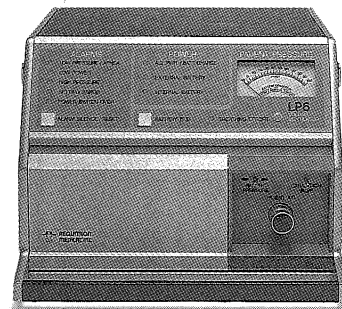
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