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1979 NATIONAL  
SPINAL CORD INJURY  
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JOURNAL

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# 1979 National Spinal Cord Injury Foundation Convention Journal

Published for the  
31st annual convention  
of the  
National Spinal Cord  
Injury Foundation  
August 5-9, 1979  
Denver, Colorado

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Editor and Publisher

ANN KAHL  
Art Director

CRISTINE SHUEY  
Assistant Editor

## *Editorial Office*

901 Arcola Avenue  
Wheaton, Maryland 20902  
Phone: (301) 649-5596

Write or call for information about  
next year's journal.

## *Convention Theme*

**Care, Cure, and Coping**

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L. Anthony Magliozzi  
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Sharon Wilkin

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The Mountain States Chapter  
and the Rocky Mountain  
Regional Office of the  
National Spinal Cord  
Injury Foundation

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Program Chairperson  
Jane Edgar  
Local Arrangements Chairperson

## *Arrangements Committee*

|                                           |                                                  |
|-------------------------------------------|--------------------------------------------------|
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| Margaret Johnson<br>Signs and Decorations |                                                  |
| Dick DeVoe<br>Exhibits                    |                                                  |

Cover photo by Roland Sharillo

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the people who read this journal.

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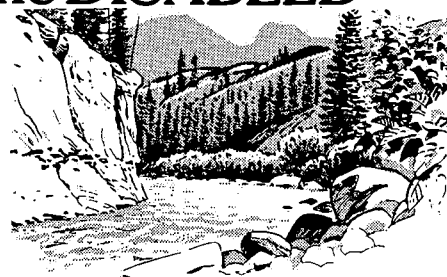
The Denver Commission on the Disabled is an advocate of the rights and needs of all handicapped residents of the City and County of Denver.

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# Convention Mailbox

## **Changes in Name, Growth, and Direction**

It is with great pleasure that I welcome each of you to the Rocky Mountains and the 31st annual convention of the National Spinal Cord Injury Foundation. During the past year the Foundation has experienced many changes—in name, growth, and direction—and I think this year's convention reflects that progress. If you look at the schedule of activities, you will find a very thorough exploration of topics of concern to spinal cord injured persons as well as to those who work or are interested in the field. This should be one of our most comprehensive meetings ever—better yet since it is being held in the Queen City of the Plains!

Congratulations are due the Mountain States Chapter and the Convention and Program Committees for putting together such a fine program. They certainly have done an outstanding job, and I would encourage you to attend as many sessions as you can.

With continued interest and support, the Foundation will be successful in spreading awareness throughout the country about the issues of spinal cord injury and the potential of disabled persons. Enjoy!

**Robert R. Jackson**  
President  
National Spinal Cord Injury Foundation

## **Para-Pete Says, "Hello"**

The members of the Mountain States Chapter and our mascot, Para-Pete, extend a warm hand of friendship to the National Spinal Cord Injury Foundation. We welcome the convention to our lovely Mile High City and trust all of you will enjoy not only the programs and meetings but also the fellowship of a national event. As hosts, we will try to make this a friendly gathering.

There is lots to see and do in the city, and the mountains are just 30 minutes away. Information is available at the hospitality desk. Please let us know if we can be of help during your stay in Denver.

**Jane Edgar**  
President  
Mountain States Chapter  
National Spinal Cord Injury Foundation



## **A Pledge of Assistance**

On behalf of the entire staff of Craig Hospital, I would like to welcome you to Denver, the "Mile-Hi" city. We are delighted that the National Spinal Cord Injury Foundation selected Denver as the 1979 convention site.

As long-time providers of care to persons with spinal cord injuries, we are extremely interested in the progress of the National Spinal Cord Injury Foundation. We are especially pleased that the Rocky Mountain Regional Office was recently opened in Denver. We know that the programs the regional office intends to pursue will benefit our graduates greatly in successful reintegration as contributing members of society in the Rocky Mountain area. We pledge our assistance in any way possible to facilitate the development of the regional office and help with programs at the national level.

**Dennis J. O'Malley**  
Administrator  
Craig Hospital

## **Denver This Year; Orlando Next**

The central office staff looks forward to seeing you in Denver. It's a great city, and the proximity of the awesome Rocky Mountains makes it a super place to visit and a wonderful vacation area. In addition, Denver is the site of the Foundation's regional office for the Rocky Mountain area, including the states of Utah, Idaho, Montana, North Dakota, South Dakota, Nebraska, Kansas, Wyoming, and, of course, Colorado.

Enjoy yourselves, and next year join us in Orlando, Florida, for the Foundation's 1980 Convention.

**Bruce E. Marquis**  
Executive Director  
National Spinal Cord Injury Foundation

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**Colorado Welcomes the Foundation**

On behalf of all Coloradans, it is a pleasure to welcome you to the National Spinal Cord Injury Foundation's annual convention being held this year in Denver. We are pleased to share the Queen City with you and hope your stay is enjoyable.

This gathering should be a good opportunity to explore the issues and concerns of people who daily deal with disabilities. The program includes a wide range of interesting and worthwhile topics. I am sure you will find your participation valuable.

Again, welcome to Colorado.

Richard D. Lamm  
Governor  
State of Colorado

**A Commendation from the Mayor**

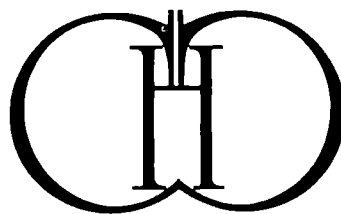
It is my pleasure and privilege to extend a warm welcome to all in attendance at the annual convention of the National Spinal Cord Injury Foundation, meeting the week of August 5-9 in Denver.

I am well acquainted with the noble work accomplished by the members of your association, and I commend and congratulate all of you for this important work in your respective communities. I am sure your convention will be useful and rewarding.

I hope everyone attending the convention, members of the Foundation, family members, and guests, will take advantage of some of the recreational and cultural facilities Denver has to offer you. Our nearby mountain areas are beautiful this time of year if you have time to visit some of these scenic sights.

Good wishes to all.

W. H. McNichols Jr.  
Mayor  
City of Denver



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# BOOSTERS

The National Spinal Cord Injury Foundation thanks these individuals, organizations, and institutions for their support of the 1979 convention journal.

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Los Angeles, California

**Col. & Mrs. Arthur W. Allen Jr.**

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# National Spinal Cord Injury Foundation Rocky Mountain Regional Office

1115 Broadway, #103  
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## Welcomes you to Denver

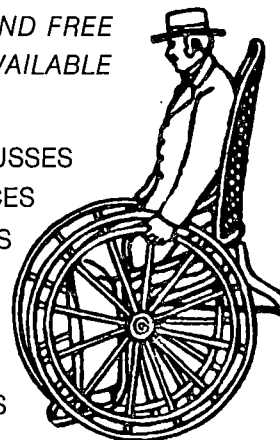
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# Convention Calendar

## Sunday, August 5

**8:00 a.m.-11:00 p.m.**

**Accessible Bus Service into Denver**

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**9:30-5:00** Lobby

**Registration Opens**

10:00-3:00 Prospectors Halls 1 and 2

Chapter Liaison Panel

Chairperson: Jean S. Logan

Director of Public Relations

Cúative Workshop

Milwaukee, Wisconsin

**10:00-4:00**

**Bus Trip to Heritage Square**

\$5 - box lunch included

**10:00-12:30** Room A

**Short Course on Nursing Management of Spinal Cord Injury\***

Mary Anne Monroe, Director of Nursing

Craig Hospital

Englewood, Colorado

Lois Schaetzle, Director of Nursing Education

Craig Hospital

Englewood, Colorado

*Concurrent Workshops for Chapter Leaders:*

**10:00 and 12:30** Queen City South

**Workshop: Recruiting Chapter Members**

Ronald Hanson

Supervisor of Regional Operations

Bureau of Vocational Rehabilitation

Augusta, Maine

**10:00 and 12:30** Prospectors Hall 3

**Workshop: Organizing Your Community**

Warren L. McManus

Assistant Commissioner for Administration and

Client Services

Massachusetts Rehabilitation Commission

Boston, Massachusetts

**10:00 and 12:30** Room C

**Workshop: Marketing Your Chapter**

Allen Horton, President

Central Florida Chapter

National Spinal Cord Injury Foundation

Orlando, Florida

**10:00 and 12:30** Room B

**Workshop: Creating Programs**

James T. Bowse

Director of Corporate Development

St. Mary's Hospital

Lewiston, Maine

\*tuition fee

12:00-1:30 Board Room

Development Committee Meeting

**1:15-2:15** Room A

**Videotapes About Nursing Management**

William C. Norris

Director of Learning Systems

Division of Mississippi Methodist Hospital

and Rehabilitation Center

Jackson, Mississippi

*Concurrent Short Courses on*

*Psychosocial Issues in Spinal Cord Injury:*

**2:00 and 3:45** Room A

**Short Course: Sexuality\***

Jack Dahlberg

Supervisor of Family Services

Craig Hospital

Englewood, Colorado

Joanne Taggie

Colorado Resource Coordinator

National Spinal Cord Injury Foundation

Denver, Colorado

**2:00 and 3:45** Room B

**Short Course: Financial Disincentives\***

Gerben DeJong, Research Associate

Tufts New England Medical Center

Boston, Massachusetts

Scott Manley

Director of Family Services

Craig Hospital

Englewood, Colorado

Bonnie Sims, Discharge Coordinator

Craig Hospital

Englewood, Colorado

**2:00 and 3:45** Room C

**Short Course: Research in Psychosocial Issues\***

Roberta Treischmann

Psychologist

Diamond Bar, California

**2:00 and 3:45** Room D

**Short Course: Assertiveness\***

Mickey Ginsberg, Clinical Psychologist

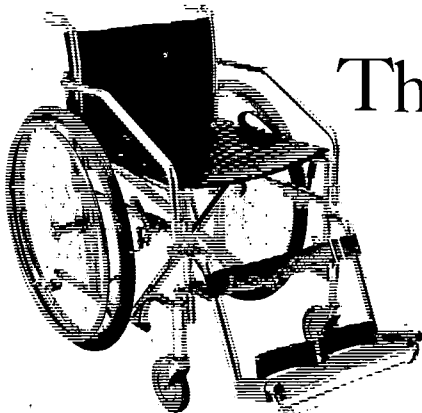
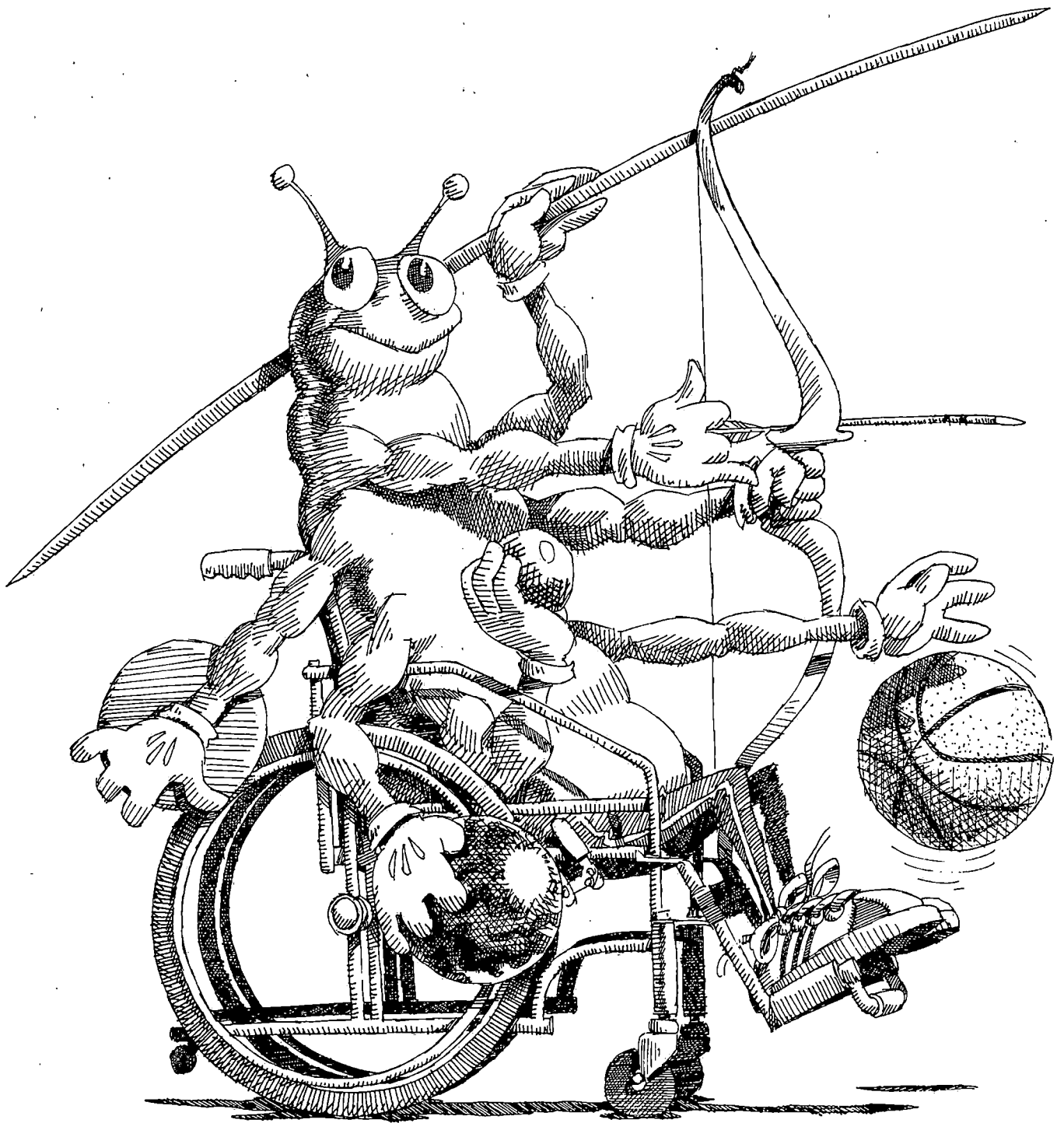
Denver General Hospital

Denver, Colorado

4:00-6:00 Prospectors Halls 1 and 2

Board of Directors Meeting

continued on page 11



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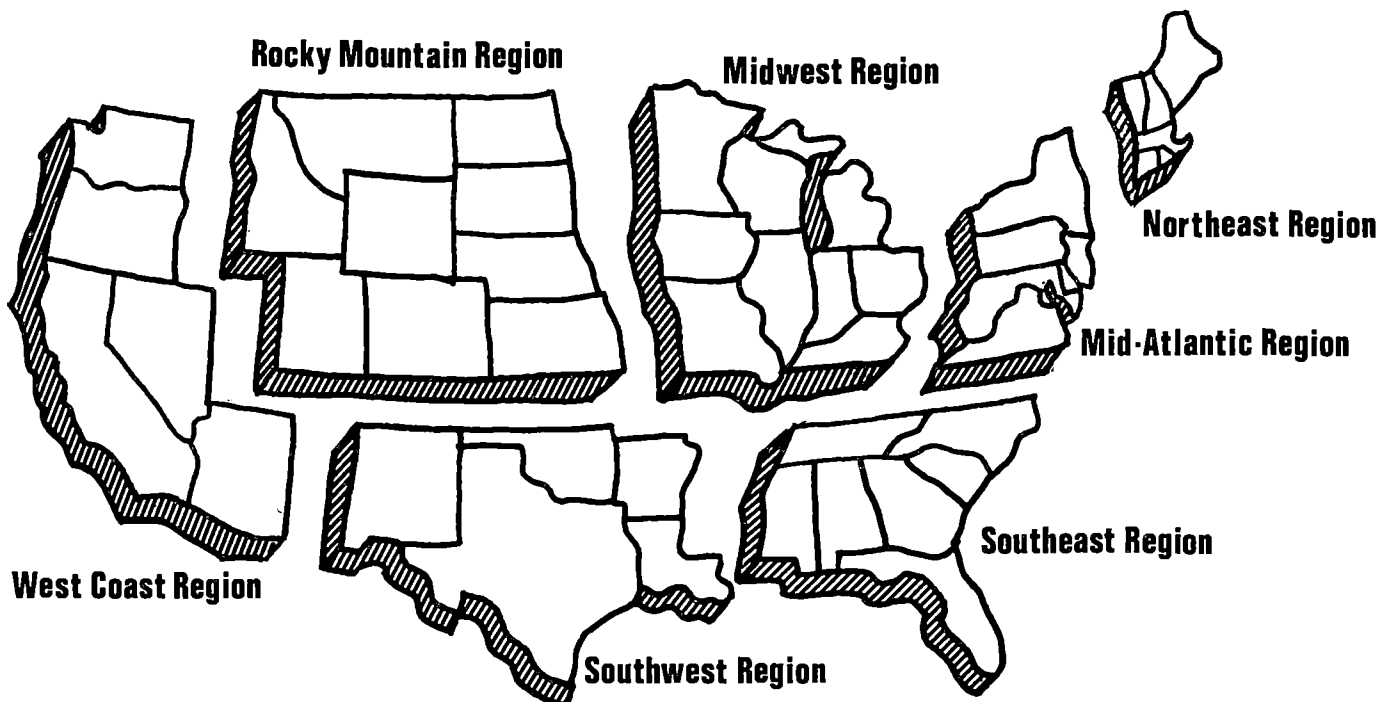
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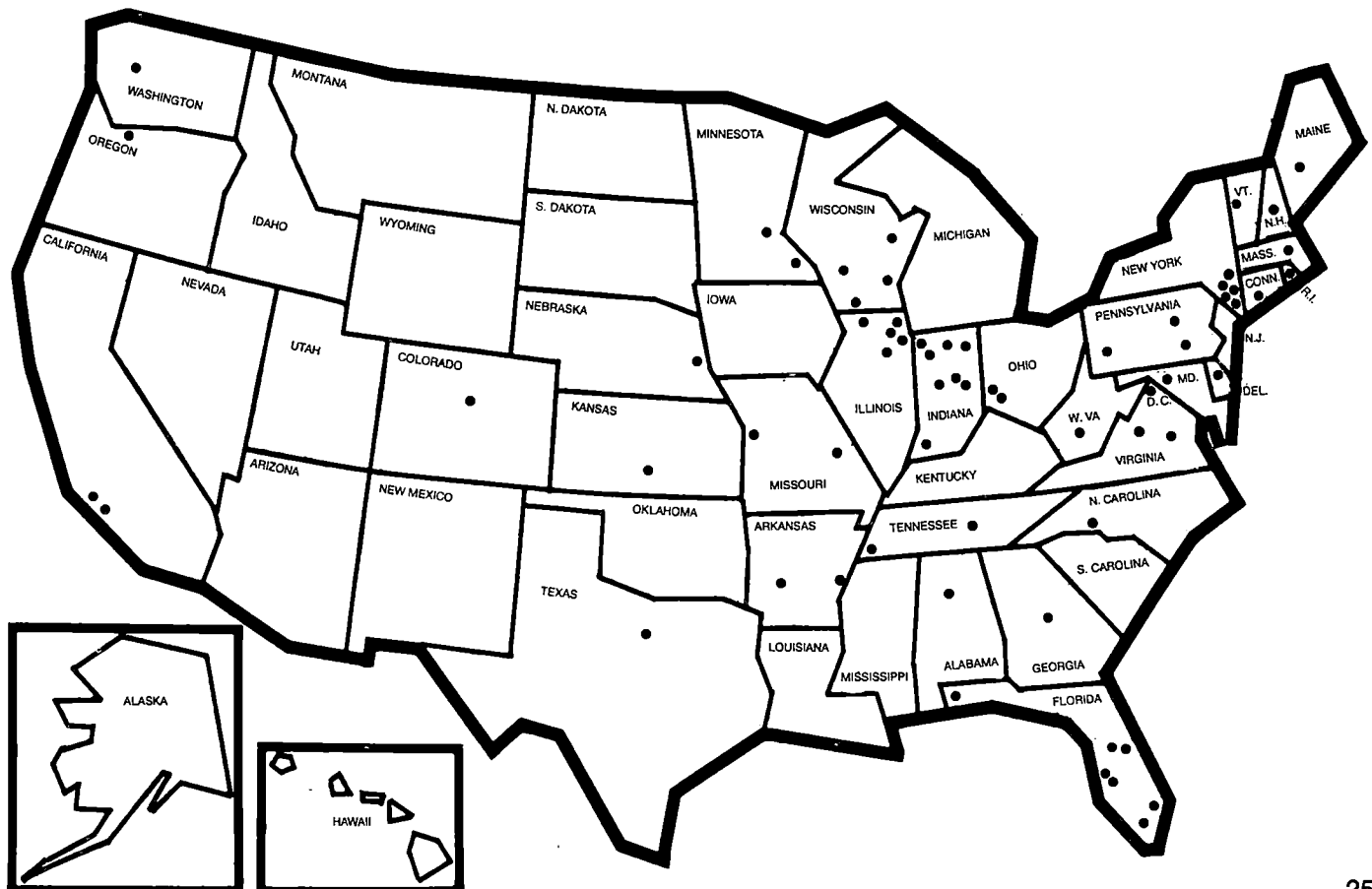
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# What Is Spinal Cord Injury?

## And What Can We Do About It?

Spinal cord injury is a lesion of the cord that results in paralysis of certain parts of the body and corresponding loss of sensation. Paraplegia refers to paralysis from approximately the waist down. Quadriplegia refers to paralysis from approximately the shoulders down.

The catastrophic nature of spinal cord injury is much more complex than loss of feeling and inability to move. Individuals who experience damage to their spinal cords also contend with impairment of bladder, bowel, and sexual function. Added to this are the psychological effects of adjustments that must be made to social, economic, and emotional ramifications of spinal cord injury.

The major causes of spinal cord injury are motor vehicle accidents (about 50% of the total), falls, diving and other sporting mishaps, and results of violence such as gunshot and stab wounds. The overwhelming majority of injuries, about 80%, are incurred by males who are, in general, between the ages of 15 and 30 when injured.

A comprehensive system is necessary to integrate care, treatment, rehabilitation, and return to independent living in the community. For this reason, regional spinal cord injury systems are under development so that available resources will be effectively coordinated. Much must be done to refine these systems and eliminate gaps in service.

The National Spinal Cord Injury Foundation, formerly the National Paraplegia Foundation, has given priority to improving methods of clinical care, developing more effective equipment and devices, and promoting basic neuroscientific research to find means of regenerating spinal cord tissue. These activities provide for better day-to-day management of spinal cord injury by consumers and providers of service and at the same time explore the long-term possibilities for finding a so-called "cure" for spinal cord injury. The National Spinal Cord Injury Foundation has a Research Division to spearhead efforts in basic and applied research.

In order to assist persons with spinal cord injuries, the Foundation has 60 chapters throughout the United States. Many members are disabled; many are not. Chapter members participate in a variety of activities. They work with local and national officials and agencies to develop better programs and services. They act as community advocates for improved access, housing, transportation, employment, and leisure time activities for disabled people. These are fundamental aspects of living that 250,000 paraplegics and quadriplegics must cope with after they have been rehabilitated and have returned to community life.

More and more persons are getting involved in activities of the National Spinal Cord Injury Foundation. Through the collective efforts of staff, chapters, board members, and other volunteers, the Foundation is improving care, producing results in research, and addressing everyday living issues that confront all wheelchair-users.

It should be noted that the Foundation serves not only persons with spinal cord injuries but also persons who have diseases or conditions the effects of which are similar to those of spinal cord injury. For example, there is multiple sclerosis, which affects young adults, primarily women. Freidreich's ataxia manifests itself during teenage years and appears to run in families. Polio still occurs, primarily in young children, even though vaccines are available. Spina bifida develops before birth during growth of the fetus. Varying degrees of paralysis often result. The individuals affected frequently use wheelchairs and therefore must cope with many of the same problems that confront persons with spinal cord injuries.

### **What the Foundation Does**

There are three basic program goals:

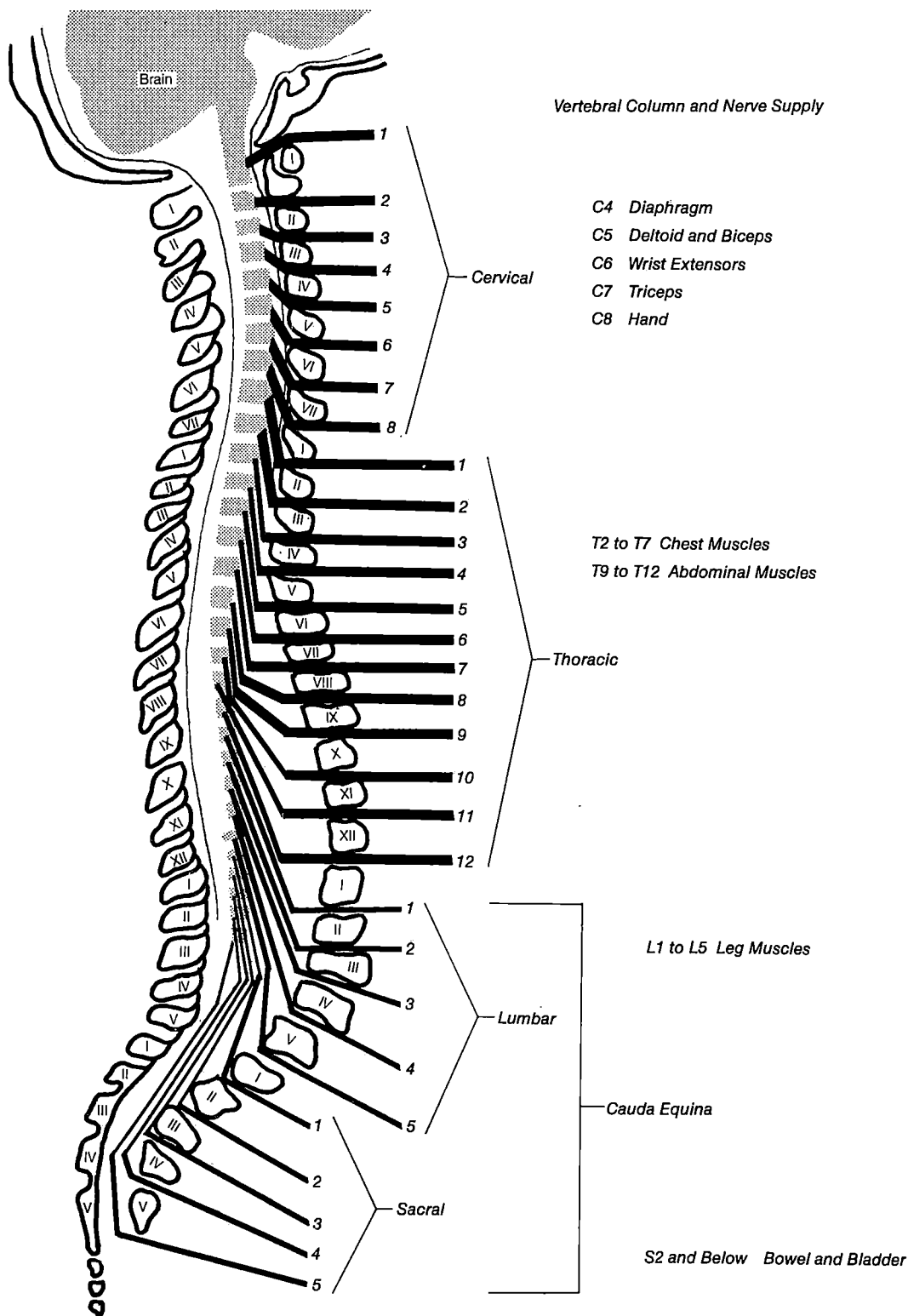
1. The National Spinal Cord Injury Foundation assists in the development of regional systems of comprehensive and integrated care, treatment, rehabilitation, and community

continued on page 29

A paraplegic is a person whose lower extremities and part of whose torso are paralyzed as a result of injury or disease of the spinal cord.

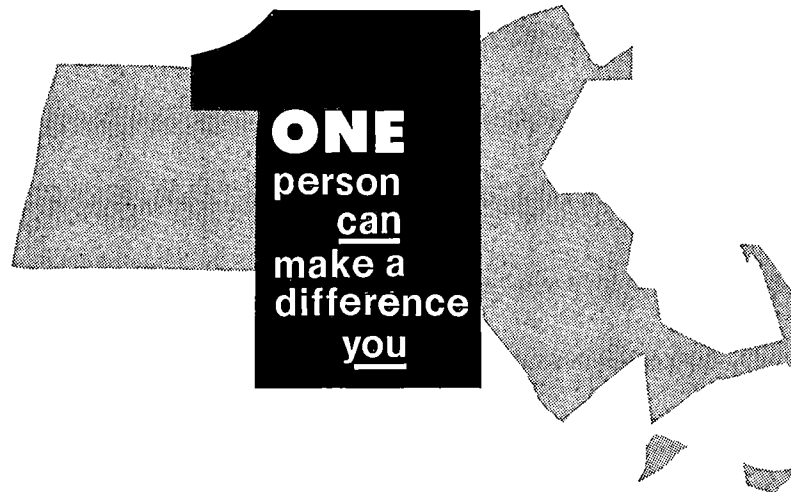
A quadriplegic (also called a tetraplegic) has in addition a paralysis of the hands and a partial paralysis of the arms.

Most paraplegics and quadriplegics have loss of sensation below the level of injury and loss of controlled function of the bladder and bowel.



A person with a spinal cord injury may be a paraplegic or a quadriplegic. This drawing represents a sagittal section of the spine. The vertebrae are labeled with Roman numerals; the spinal nerves are labeled with Arabic numbers. The muscles and organs controlled by various nerves are listed on the right. When spinal cord injury occurs, the level is designated by calling the person, for example, a C4-5 quadriplegic. Paraplegia results from injury at the T1 level or below, and quadriplegia results from injury at the C8 level or above.

# Massachusetts Association of Paraplegics, Inc.



**An organization open to both handicapped and able-bodied individuals. It was originally organized in 1965 by paraplegics but has now grown to include people of all disabilities who are concerned with:**

- a. eliminating architectural barriers (any man-made structure that limits the daily activities of an individual)
- b. increasing accessible housing for all handicapped individuals
- c. creating and improving employment opportunities for the handicapped
- d. improving education on all levels and facilitating the distribution of information on local educational institutions
- e. speaking before groups and organizations concerning various disabilities and clarifying the problems and potential of the handicapped
- f. initiating and supporting legislation for the benefit of the handicapped community as a whole

**MAP members have influenced the establishment of:**

- a. *Bay State Wheelchair Games* — An annual event attracting wheelchair athletes and aspiring athletes from all parts of the country.
- b. *Worcester Wheelers Bowling League* — A bowling league made up of and open to adults with various kinds of physical handicaps. It offers recreation, exercise, and social activities to those who might otherwise become shut-ins.
- c. *Baystate Wheelers Basketball Team* — A group of disabled men who practice regularly and play benefit games in their wheelchairs.
- d. *Worcester Area Transitional Housing, Inc.* — A program designed to teach young adults with various types of severe disabilities to eventually live independently in the community. It is located at 507-J Main Street, Worcester, Mass. 02172.

**What do we expect from you as a member? INVOLVEMENT in the form of:**

- a. attending MAP meetings when possible and sharing your thoughts and ideas with others
- b. writing and telephoning fellow members and officials on issues concerning the handicapped
- c. increasing community awareness of the potential and needs of those individuals with handicaps
- d. acting as consultant-advocate on behalf of the disabled
- e. referring persons with disabilities to MAP as a source of help and information
- f. presenting the handicapped as a vital, productive part of the community

**What can you expect from MAP? HELP in the areas of, but not limited to: employment, education, housing, equipment, homemaking, recreation, and legislation.**

**MAP publications:**

- a. The MAP Newsletter (\$2 per year, free to members)
- b. MAP Annual Report
- c. Housing Needs of the Handicapped (1970)
- d. A Resource Guide for the Disabled of Massachusetts (1975) (\$2)

**MAP affiliations:**

- a. Mass. Council of Organization of the Handicapped (MCOH)
- b. National Paraplegia Foundation (NPF)
- c. American Coalition of Citizens with Disabilities (ACCD)

**MAP officers:** An updated listing of officers, Board members and committee chairpersons may be obtained from the address below.

## Offical State-wide Chapter of the National Spinal Cord Injury Foundation

369 Elliot Street  
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living. The purpose is to serve individuals who become paralyzed as a result of spinal cord injury. Activities include:

- promoting ideal standards of care;
  - documenting available resources;
  - coordinating resources at the local level;
  - providing case consultation services to persons who have recently experienced spinal cord injury and their families;
  - developing and providing independent living services that help high-level quadriplegics and others with severe physical disabilities make the transition from dependent situations to independent community lifestyles;
  - educating professionals about proper methods of providing care and rehabilitation; and
  - implementing a program of public education that focuses on prevention of spinal cord injury and abilities of individuals who have been paralyzed as a result of spinal cord injury.
2. The National Spinal Cord Injury Foundation supports and encourages research aimed at improving care for persons with spinal cord injury and developing a cure for spinal cord injury and disease. To pursue these objectives, the following activities are undertaken:
- promoting neuroscientific research;
  - promoting improved clinical care through professional education and support of research conducted by other agencies and organizations;
  - promoting research to improve equipment and special devices;
  - providing fellowships for postdoctoral researchers working on basic neuroscientific problems;
  - sponsoring biennial conferences on basic neuroscientific research;
  - publishing scholarly research bibliographies; and
  - facilitating exchange of information between and among scientists.
3. The National Spinal Cord Injury Foundation pursues resolution of issues related to the everyday lives of paraplegics and quadriplegics. Problem areas include access, housing, transportation, employment, and leisure. Activities are carried out primarily through the chapter structure of the Foundation. Specifically, chapters:
- provide peer counseling on a person-to-person basis;
  - help through personal contact to motivate individuals with spinal cord injury to establish realistic goals in regard to employment, education, transportation, and adaptation to wheelchair living;
  - distribute information to paraplegics, quadriplegics, and others in regard to equipment, personal care, special devices, and other important resources; and
  - advocate elimination of barriers to independent living for persons who use wheelchairs for mobility.

#### What You Can Do

The National Spinal Cord Injury Foundation needs your support and involvement. You can help by:

- joining the Foundation;
- volunteering to assist with its local, regional, and national programs;
- contributing money to support the services of the Foundation and identifying others who can help; and
- speaking with your local, state, and national representatives in government about the needs and abilities of spinal cord injured people. □

## KANSAS PARALYSIS CHAPTER OF NATIONAL SPINAL CORD INJURY FOUNDATION

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# The Year in Review

by Bruce E. Marquis



Fiscal year 1978 has been a time of innovation as well as renewal; expansion as well as consolidation; changes as well as the continuation of tradition. Marking the Foundation's 30th Anniversary, the fiscal/program year 1978-1979 has been a time of excitement and growth for our organization.

In May of 1978 the Board of Directors accomplished a merger between the National Paraplegia Foundation and the New England Spinal Cord Injury Foundation, in effect combining the two organizations most dedicated to improving care for civilians with spinal cord injuries. Bruce Marquis was appointed Executive Director and the Central Administrative Office was shifted from Chicago, Illinois, to Newton Upper Falls, Massachusetts.

Demonstrating their renewed commitment to persons with spinal cord injury, the members of the foundation voted overwhelmingly to change the organization's name to National Spinal Cord Injury Foundation, effective January 1, 1979.

Through the creation of regional service offices, the essential foundation programs of care, cure, and coping were expanded nationwide. Regional offices were established in Newton Upper Falls (New England), Milwaukee (Midwest), and Denver (Rocky Mountains). Regional development has begun in Orlando (Southeast), San Francisco (West Coast), and Washington, D.C. (Mid-Atlantic).

Chapter growth and development has witnessed a dramatic increase this fiscal year, and twelve state chapters have been established:

|             |               |
|-------------|---------------|
| Alabama     | Maine         |
| Colorado    | New Hampshire |
| Connecticut | Oregon        |
| Florida     | Tennessee     |
| Illinois    | Wisconsin     |
| Indiana     | Vermont       |

These joined the existing state chapters: Arkansas, Georgia, Massachusetts, and Rhode Island.

## Membership Increases 40%

Response to the Foundation's growth and renewal has been overwhelmingly positive, as is reflected in the jump in membership from 3,500 to 5,000 persons. A member of the National Spinal Cord Injury Foundation is a person who pays a minimum of \$5 in dues and pledges to support the mission and goals of the organization.

## National Resource Directory Published

Providing information that enables persons with physical disabilities to manage their lives more effectively is a programmatic hallmark of the Foundation. Fiscal year 1978 witnessed the publication of the 1979 *National Resource Directory*, the most comprehensive document of its kind. 10,000 copies were distributed throughout the country.

## Jordan Fellowship Program Continues

For the third consecutive year, the Foundation will award post-doctoral research fellowships to outstanding young scientists to study the processes involved in regeneration of the spinal cord. This support has been instrumental in promoting the investigations of some of the most gifted and dedicated scientists in the world.

## Independent Living Rehabilitation Programs

Five independent living rehabilitation programs, which enable persons with spinal cord injuries and other severe physical disabilities to regain and maintain productive lives in the community, have been established in Southeastern and Northeastern Massachusetts, New Hampshire, Rhode Island, and Maine.

## Biennial Conference on Regeneration Conducted

Fort Lauderdale, Florida, was the site of the fifth biennial conference on Regeneration in the Central Nervous System held May 7-9, 1979. The conference convened the nation's outstanding scientists in this field for information-sharing and professional advancement.

## Corporate Support Strengthens

Several major corporate contributions were received this year to support the Foundation's programs: Everest & Jennings provided \$20,000 to underwrite the costs of printing the *National Resource Directory*; McDonalds' Corporation donated \$7,000 to cover publication costs of *The Handbook of Care for Paraplegics and Quadriplegics*; and an Insurance Industry Campaign has resulted in a contribution of \$68,000 over the next three years.

## National Wheelchair Marathon

By far the most powerful public education program of the Foundation, the National Wheelchair Marathon, was conducted for the third time in conjunction with the famous Boston Marathon on April 16, 1979. Ken Archer of Akron, Ohio, became the new national champion with a winning time of 2:38:59.

## Wheel-A-Thons See Second Year

Spring 1979 marks the second year for this chapter fund-raising event. The number of chapters conducting Wheel-a-thons has more than quadrupled from last year. □

Bruce Marquis is executive director of the National Spinal Cord Injury Foundation.

# National Spinal Cord Injury Foundation Finances

## Balance Sheets — June 30, 1979, 1978, and 1977

|                                                                   | 1979             | 1978             | 1977             |
|-------------------------------------------------------------------|------------------|------------------|------------------|
| Cash .....                                                        | \$ 43,297        | \$ 39,521        | \$ 16,901        |
| Certificates of deposit .....                                     | 40,000           | 35,000           | 48,000           |
| Accounts receivable, net of allowance for doubtful accounts ..... | 72,191           | 5,838            | 4,227            |
| Prepaid expenses .....                                            | 7,542            | 5,524            | 6,841            |
| Fixed assets, at cost, net of accumulated depreciation .....      | 11,110           | 8,189            | 2,372            |
| <b>Assets .....</b>                                               | <b>\$174,140</b> | <b>\$ 94,072</b> | <b>\$ 78,341</b> |
| Notes payable to banks .....                                      | \$ 44,000        |                  | \$ 5,000         |
| Accounts payable .....                                            | 51,752           | 39,809           | 11,768           |
| Withheld and accrued payroll taxes ..                             | 24,159           | 2,732            | 1,622            |
| Deferred income .....                                             |                  | 7,215            | 14,024           |
| Installment notes payable .....                                   | 8,941            | 7,490            |                  |
| Total liabilities .....                                           | \$128,853        | \$ 57,246        | \$ 32,414        |
| General fund (deficit) .....                                      | \$ (252)         | \$(34,325)       | \$(28,878)       |
| General fund — unappropriated ....                                |                  | 1,658            | (9,585)          |
| Donor restricted fund .....                                       | 42,652           | 66,606           | 81,627           |
| Endowment fund .....                                              | 2,887            | 2,887            | 2,763            |
| Fund balances .....                                               | \$ 45,247        | \$ 36,826        | \$ 45,927        |
| <b>Liabilities and fund balances .....</b>                        | <b>\$174,140</b> | <b>\$ 94,072</b> | <b>\$ 78,341</b> |

## Contributions, Revenues, and Expenses for the Years Ended June 30, 1979, 1978, and 1977

|                                                                    | 1979             | 1978             | 1977             |
|--------------------------------------------------------------------|------------------|------------------|------------------|
| Contributions from individuals and organizations .....             | \$202,751        | \$121,827        | \$150,607        |
| Contributions from chapters .....                                  | 24,303           | 22,312           | 19,521           |
| Total contributions .....                                          | \$227,054        | \$144,139        | \$170,128        |
| Dues .....                                                         | \$ 32,185        | \$ 27,513        | \$ 18,504        |
| Convention .....                                                   | 15,905           | 24,542           | 17,440           |
| Publications .....                                                 | 12,267           | 23,885           | 17,387           |
| Government grants and contracts ..                                 | 431,390          |                  | 3,570            |
| Special events .....                                               | 68,892           | 23,490           | 19,670           |
| Contracted services .....                                          | 8,000            | 1,758            | 1,960            |
| Exhibit fees .....                                                 |                  | 3,658            |                  |
| Miscellaneous, primarily interest income .....                     | 4,911            | 2,983            | 2,552            |
| Total revenues .....                                               | \$573,550        | \$107,829        | \$ 81,083        |
| <b>Total contributions and revenues ..</b>                         | <b>\$800,604</b> | <b>\$251,968</b> | <b>\$251,211</b> |
| Expenses for awards and grants ....                                | \$ 24,248        | \$ 35,542        |                  |
| Salaries and outside services .....                                | 371,262          | 79,375           | 95,485           |
| Printing and publications .....                                    | 71,911           | 46,181           | 37,698           |
| Supplies .....                                                     | 41,679           | 24,816           | 19,841           |
| Meetings .....                                                     | 40,896           | 15,153           | 14,071           |
| Building occupancy .....                                           | 19,666           | 16,780           | 14,774           |
| Professional fees .....                                            | 23,917           | 9,066            | 10,772           |
| Postage and shipping .....                                         | 13,556           | 7,401            | 5,204            |
| Employee benefits .....                                            | 74,252           | 5,620            | 7,642            |
| Payroll taxes .....                                                |                  | 3,560            | 4,580            |
| Telephone and telegraph .....                                      | 28,990           | 7,121            | 8,859            |
| Travel .....                                                       | 61,223           | 3,366            | 6,359            |
| Support for other organizations ....                               | 957              | 1,429            | 380              |
| Miscellaneous .....                                                | 24,678           | 2,186            | 3,304            |
| Disbursements for individuals .....                                | 15,660           | 200              | 12,624           |
| Bad debts .....                                                    |                  | 1,600            |                  |
| Depreciation .....                                                 | 5,087            | 1,673            | 924              |
| <b>Total functional expenses .....</b>                             | <b>\$816,068</b> | <b>\$261,069</b> | <b>\$242,507</b> |
| Excess (deficit) of contributions and revenues over expenses ..... | \$(15,464)       | \$ (9,101)       | \$ 8,694         |
| Fund balance, beginning of the year .....                          | 36,826           | 45,927           | 37,233           |
| <b>Fund balance, end of the year ....</b>                          | <b>\$21,362</b>  | <b>\$36,826</b>  | <b>\$45,927</b>  |

These figures are based on audited financial reports, except that 1979 figures include fourth-quarter projections. Additional information is available from the Central Administrative Division of the Foundation.

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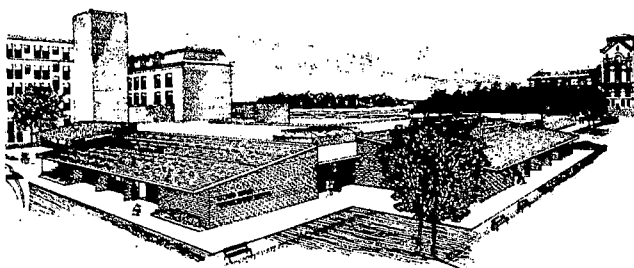
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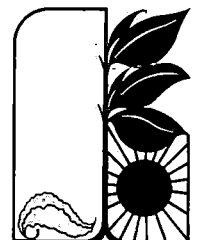
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# Foundation Sponsors Neuroscientific Conference

by Richard P. Veraa

Forty-four scientists from the United States, Canada, England, and Sweden gathered in Fort Lauderdale, Florida, May 7-9 for the Foundation's Fifth International Conference on Regeneration in the Central Nervous System. As at previous conferences in this series, the participants represented many disciplines including anatomy, biochemistry, biology, neurology, neuropathology, neurosurgery, pharmacology, and physiology. Each brought his or her own specialized expertise, perspectives, and recent research findings to bear on the single overwhelming question of restoring function to the damaged spinal cord.

Over a year's planning by the Foundation's Scientific Advisory Committee under the chairmanship of Bernice Grafstein contributed to the success of the meeting. Further assistance came from a liaison panel designated by the Society for Neuroscience, whose cosponsorship of this year's conference attests to the importance of this topic in the scientific community.

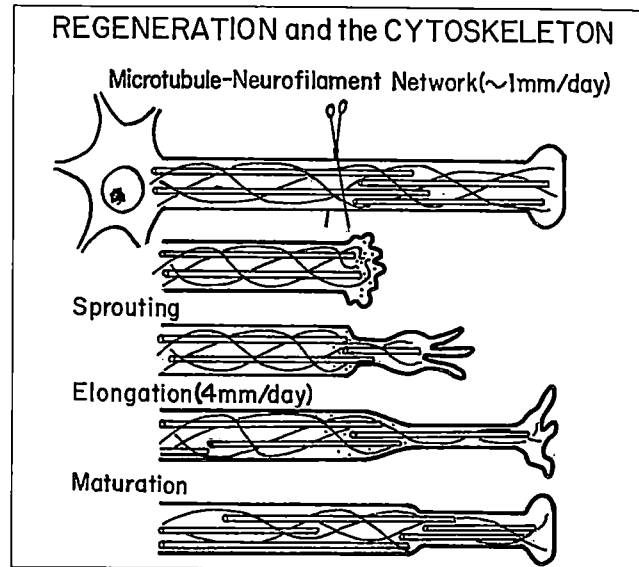
Presentations at the conference covered a broad spectrum of approaches to the problem of recovery from injury to the nervous system, ranging from the identification of factors that might promote neuronal survival and axonal regeneration to restoration of functional properties of the spinal cord by application of a neuroprosthesis. Every topic was selected with a view toward stimulating participants to concentrate on underlying *mechanisms* rather than simply describing observed phenomena.

## The Damaged Spinal Cord

The conference opened with an overview of the properties of the neurologically isolated spinal cord. When the spinal cord is damaged, profound changes occur within the cord itself. Knowledge of the functional and morphological properties of the cord after its connections with the brain have been severed is therefore of fundamental importance in understanding paraplegia and quadriplegia and in formulating strategies for reversal of these conditions. Lorne Mendell of the Department of Physiology at Duke University Medical Center, Thomas A. Sears of the Department of Neurophysiology at the National Hospital in London, Sten Grillner of the Department of Physiology at the Karolinska Institute in Stockholm, and Michael Goldberger of the Department of Anatomy at the Medical College of Pennsylvania discussed their recent studies of alterations of reflex functions in the transected spinal cord from the combined viewpoints of electrophysiological activity, microscopic anatomy, and behavioral consequences.

## Bladder Function After Injury

The second session of the conference was entitled "Mechanisms of Urinary Bladder Regulation and Prospects for Re-



*Above is a schematic drawing of events involved in reorganization of the cytoskeleton when the axon is cut. Neurofilaments and microtubules accumulate in the cut stump during the period when the growth cone is forming. This accumulate pool of neurofilament and microtubule protein may provide the materials from which the cytoskeleton is formed as the axon elongates. During maturation the newly regenerated axon increases in diameter. Raymond Lasek explained at the conference that this increase in diameter may represent the continued advance of the microtubule-neurofilament network from the parent axon into the regenerate. Full-length proceedings of the conference will be published.*

storage of Bladder Function Following Spinal Cord Injury." This session intensified the focus of the previous one in emphasizing a specific spinal cord circuit of vital importance to paraplegics and quadriplegics. Arthur Loewy of the Department of Anatomy and Neurobiology at Washington University School of Medicine in St. Louis opened the session by describing the incredibly complex interactions of the sympathetic and parasympathetic nervous systems with the central and somatic nervous systems in the process of bladder function, and William C. de Groat of the Department of Pharmacology at the University of Pittsburgh Medical School discussed the equally complex alterations in these systems following spinal cord injury, particularly the reorganization that occurs as bladder reflex activity develops. Gaylan Rockswold of the Department of Neurosurgery at the University of Minnesota described experiments in animals to elicit bladder function by electrical stimulation of the bladder itself

continued on page 35

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### Neuroscientific Conference from page 33

and the nerves leading to it, and Blaine Nashold of the Department of Neurosurgery at Duke University Medical Center reported on 27 human patients in whom bladder function had been restored by the use of an electrical stimulator in the sacral part of the spinal cord.

Apart from the exciting possibilities these techniques may offer persons with complete lack of bladder function, the session was notable for the interchange and mutual involvement between basic and clinical scientists that will become increasingly important as wider clinical applications are made possible by increased basic knowledge. This was underlined in the general discussion at the close of the session by Robert D. Wurster of the Department of Physiology at Loyola University Medical Center, who discussed autonomic and central nervous interactions in general and specifically interactions through these pathways between the bladder and the heart that may be of great importance in understanding the mechanisms of autonomic dysreflexia.

### Neuron Survival and Growth

The third session, dealing with chemical factors promoting the survival and growth of neurons, may be considered the keystone of the conference program, as it covered some of the most significant developments of recent years and provided a conceptual framework that influenced virtually all discussions throughout the meeting. As recently as the last conference in this series (1976), only one known chemical had been shown to affect the growth of nerve cells. This chemical, called Nerve Growth Factor, was discovered 30 years ago and affects only certain classes of autonomic and sensory neurons. The existence of similar factors specific for other types of neurons was hypothesized long ago, but there was no proof until recently.

Ruben Adler of the Department of Biology at the University of California in San Diego reported the discovery of such a factor, one that promotes the growth and survival of ciliary ganglion cells. These cells control the muscles of the eye, and the factor is found in the highest concentrations in the specific muscles innervated by the neurons on which it acts. In the course of isolating this factor, Adler found a second and distinct factor that induces the neurons affected by the first factor to grow fibers. Patricia Walicke of the Department of Neurobiology at Harvard Medical School reported on the discovery of a chemical produced by muscle cells that has the power to completely alter the course of development of nerve cells, causing cells of one type (adrenergic) to change into cells of a completely different type (cholinergic) with completely different chemical and metabolic characteristics. Finally, Gerald Fischbach of the Department of Pharmacology at Harvard Medical School described the discovery of a chemical produced by nerve cells that is necessary for establishment of receptive connection sites on their target tissues.

The discovery of these factors supports the hypothesis that virtually all factors of nerve cell growth and development—and eventually regeneration—are controlled by chemical activities. Tasks in the coming years will involve identification of still more chemical factors through such techniques as medium-conditioning, the tedious process of identifying each factor by sophisticated biochemical techniques, and elucidation of the precise mechanism by which each factor acts on neurons.

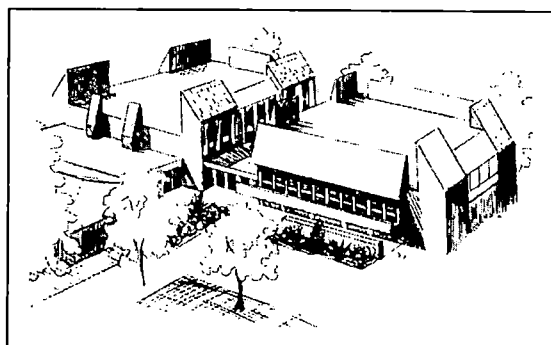
### The Influence of Supportive Cells

The fourth session of the conference examined the responses of glial cells—the supportive cells that surround

continued on page 37

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### Neuroscientific Conference from page 35

neurons in the nervous system—to injury. These “satellite” cells received little attention for many years, but during the past decade they have been recognized as vital to all the processes of growth and regeneration. Silvio Varon of the Department of Biology at the University of California in San Diego, Amico Bignami of the Department of Neuropathology at Harvard Medical School, and Leif Hertz of the Department of Anatomy at the University of Saskatchewan in Saskatoon described recent observations shedding new light on the wide range of complex interactions between glia and neurons throughout the entire spectrum of growth, survival, and regeneration. This session extended the concepts of the preceding one, in that it was shown that most of these influences are mediated by specific and specialized chemicals produced by the glial cells.

### Regeneration of the Axon

The fifth session, “Factors Regulating Axonal Regeneration,” opened with papers by Raymond Lasek of the Department of Anatomy at Case Western Reserve University and Mark A. Bisby of the Division of Medical Physiology at the University of Calgary, who discussed the transport of materials required for regeneration of fibers from the cell body down along the fiber to the cut tip. Different types of chemicals are transported at several different rates of speed in both normal and regenerating fibers. Lasek concentrated on the slow transport of materials required for the filaments and tubules that provide the skeletal framework of the fiber and asked the question, Is the axon always prepared to regenerate? By comparing transport in both normal and regenerating axons, he concluded that the answer was yes; the supply of proteins needed to normally maintain the axon is sufficient for regeneration. He went on to describe the mechanisms by which the skeletal architecture of the neuron is reconstituted during regeneration. (See drawing.)

Bisby studied the more rapidly transported materials that are involved with transmitter release, axon metabolism, and maintenance of the cell membrane. Although he noted many changes in this transport system following injuries, he concluded that since rapidly-transported materials are quickly turned over in the normal neuron, an axon shortened by injury may actually require less fast-transported material for regeneration than an intact axon. He also described studies of materials transported in the opposite direction (from the axon tip back to the body), which may provide chemical signals to the cell body that damage has occurred.

It appeared from these studies that the failure of central axons to regenerate is less a problem of the neuron itself than of the environment—particularly the chemical environment—through which the fibers must grow. Presentations by Albert J. Aguayo of the Department of Neurology at McGill University in Montreal and Carl C. Kao of the Department of Anatomy at Georgetown University in Washington described attempts to gain information on the environmental differences between peripheral nerves, which do regenerate, and central nerves, which do not. They reported on a variety of experiments in a number of different systems in which either peripheral or central tissues had been implanted into lesions of the peripheral and central nervous systems. In all cases, fibers were observed to grow more profusely into tissues of peripheral nervous system origin or cultured cells derived from it. Kao reported on an extensive series of electronmicroscopic studies comparing regeneration in the central and peripheral nervous systems. He also developed a new hypothesis to explain why it is more difficult for central nerve fibers to grow

through the physical structural environment of the central nervous system than through the environment of the peripheral nervous system.

These observations were of great interest to several other conference participants who have concentrated more on cellular effects. Similarly, many of the chemical phenomena described by other researchers should be of great value to Aguayo and Kao in their future surgical experiments.

### Formation of Synaptic Connections

The topic of the final session of the conference was trans-synaptic mechanisms regulating the formation of synaptic connections. The establishment of correct synaptic connections is likely to be one of the last steps—but an essential step—in any process of nervous system regeneration. This implies the operation of selectivity mechanisms of some kind. Therefore the last session of the conference was concerned with selectivity mechanisms that are not determined solely by the neuron and the cell upon which the connections are made and also interactions between the neuron making the connections and other neurons higher in the nervous system that connect to it. Ira B. Black of the Department of Neurology at Cornell University Medical College described a series of studies of the development of animals in which either innervating neurons or their target cells had been selectively destroyed. He discovered a pattern of mutual interdependence that provided eloquent evidence for all the effects one might expect to derive from the chemical factors previously described by Adler, Walicke, and Fischbach.

Finally, Stephen D. Roper of the Department of Anatomy at the University of Colorado Medical Center and Michael J. Dennis of the Department of Physiology at the University of California Medical Center in San Francisco described recent work on the selectivity of connections with their appropriate target organs. Roper showed that the regeneration of pre-synaptic axons in the cardiac ganglion of frogs is inhibited by previously existing connections, and Dennis described the elimination of inappropriate connections in the development of nerve-muscle synapses in the intercostal muscles of the rat. It was hypothesized many years ago that selectivity of synapses might be mediated by some chemical forces, but the nature and action of the chemicals involved remain to be explained. The recent discoveries of chemical factors with enormous consequences for growth and development will surely give new impetus for the precise identification of the nature and mechanisms of factors in this area as well.

### A Word of Caution to the Reader

The reader should be cautioned that this article has summarized to the extent of gross over-simplification in many cases. Topics discussed at the conference will be placed in the perspective of their relative importance to scientists and to quadriplegics and paraplegics by Bernice Grafstein in her report to the Foundation at this year's national convention. It is hoped, however, that these brief glimpses of the proceedings will give the reader some idea of the scope and magnitude of concepts developing in the quest to promote central nervous system regeneration. There are many interactions. A wide variety of mutually important approaches must be taken, combined with work in all other areas, and finally synthesized into an overall understanding if a solution to the problem of regeneration is to be found. □

# Foundation Fellowships for Young Researchers

For the third year, the National Spinal Cord Injury Foundation has awarded postdoctoral research fellowships to outstanding young scientists for the study of processes involved in regeneration of the spinal cord. The three 1978 fellowship recipients, now completing the term of their awards, have already reported significant findings and productive work, which will be described in *Paraplegia Life* this fall upon completion of their projects. The outstanding quality of applicants, both last year and this, has been a gratifying indication of the interest among young scientists in the problem of spinal cord injury. Although worthy applications have exceeded the Foundation's resources by tenfold, our support has been instrumental in promoting the work of some of the most gifted and dedicated investigators in the world.

The fellowship program also has served to demonstrate the need for support of promising young scientists, and we are gratified that the National Institute of Neurological and Communicative Disorders and Stroke has during the past year significantly increased its share of Federal funding in this area, effectively complementing our efforts in the private sector.

Major funding for the Foundation's program is made possible by the generosity, dedication, and foresight of R.S. Jordan, a member of the Foundation board of directors.

## **Thomas M. Brushart, Jordan Fellow**

The recipient of the \$15,000 Jordan Fellowship for 1979-80 is Thomas M. Brushart, 30 years old. Born in Washington, D.C., he received his B.A. degree in biology *magna cum laude* from Harvard College and his M.D. in 1976 from Harvard Medical School. His interests have ranged from biology, arctic, and oceanographic research to orthopedic and neurological surgery.

While working as an instructor in anatomy at Harvard in 1978, Brushart's interests turned to problems of neurological regeneration. First, he was able to establish a method for demonstrating motor and sensory connections of peripheral nerves and individual muscles. The ability to demonstrate central sensory projections of peripheral nerves is a relatively important contribution to neuroanatomy, and this work is now in press in the journal *Neuroscience*. Furthermore, Brushart has been able to demonstrate the reorganization of central connections following nerve repair. Although suspected, this had never been demonstrated before and offers an anatomical explanation for the poor motor coordination that follows peripheral nerve repair. In the course of these experiments, Brushart was also able to compare different types of nerve



repair and to note that the method of repair influences the specificity of subsequent regeneration.

Brushart has noted that recovery after peripheral nerve repair is often unsatisfactory, with persistent disturbances of both sensory and motor function. These disturbances have been attributed by many investigators to the misalignment of axons at the repair site, which disrupts organizational relationships between the central and peripheral nervous system. As early as 1953, S. Sunderland advocated microsurgical

continued on page 41

## The National Spinal Cord Injury Foundation Announces the Jordan Fellowship and Foundation Research Fellowships for Biomedical Research in Central Nervous Regeneration

The National Spinal Cord Injury Foundation will consider applicants from accredited medical schools and universities for grants to support annually a limited number of fellowships.

The Foundation wishes to support individuals of unusual originality in biomedical research. Awards are intended to help promising young postdoctoral investigators in early stages of their careers, rather than to assist in the support of well established individuals to whom more general sources of funds may be available.

The area of the proposed program of research may be in any biomedical discipline and should relate to the elucidation and understanding of growth and regeneration in the central nervous system as it may eventually apply to the prevention or reversal of paralysis caused by injury or disease of the spinal cord. It is the hope and aim of the Foundation to contribute to the alleviation of suffering caused by spinal cord injury or disease.

### Fields of Study and Conditions of Appointment

Awards will be made for research work in any field of biomedical science approved by the Foundation and a panel representing its Medical and Scientific Advisory Committees. The research project awarded must begin within the fiscal year it is granted (beginning July 1).

All research work by a Fellow is to be under the guidance of a qualified investigator designated by the school. Fellows are expected to devote the major portion of their time to research, but may include some study and clinical experience in allied fields. The medical school or university must agree to supply adequate equipment, laboratory facilities and supplies.

Quarterly reports are to be submitted to the Research Director of the Foundation covering the principal results of the research and fellowship experience. All published papers resulting from research performed as a National Spinal Cord Injury Foundation Fellow should carry a suitable footnote acknowledgment and one reprint should be sent to the Foundation.

### Qualifications of Applicants

Fellowships are open to applicants who have attained the degree of Doctor of Medicine or Doctor of Philosophy. Preference will be given to applicants who have attained this degree within three years of the commencement of the fellowship period. Applicants must be sponsored by an accredited medical school or university.

### Amount and Term of Fellowship

Foundation Fellowship appointments are for one-year periods. As a rule, stipends will not exceed \$12,000 plus \$500 per dependent of any given applicant. At the discretion

of the Evaluation Panel no more than one fellowship per year, to be designated the Jordan Neuroscientific Research Fellowship, may be awarded to one outstanding applicant with a stipend of \$15,000.

The sources and amount of other income that the applicant expects to receive during the period of the Fellowship should be clearly stated in the application. While other income will not preclude favorable consideration of an application, preference will be shown to applicants whose major source of income will be the fellowship award. Applications for renewal of award will be competitive with all other applications.

### How to Make Application

Individuals should apply through any accredited medical school or university for a National Spinal Cord Injury Foundation Fellowship. The applicant and his cooperating school should join in preparing information for presentation to the Foundation in accordance with instructions. Application forms are available from the Foundation.

All applications should be received by the Foundation prior to April 1 for awards during the following fiscal year.

### Application Instructions

Information to accompany applications and renewals:

1. A curriculum vitae and bibliography of publications.
2. Scholastic records — medical school and/or graduate school transcript.
3. Two descriptions of the proposed medical research, one in nontechnical language less than 200 words. The technical outline should state the significance of the problem and include plans for solving it, hypotheses, methodology, and expected results.
4. Letters from the director and/or project supervisor of the department in which the work will be done stating:
  - a. that the applicant will be accepted.
  - b. that facilities and supplies will be available.
  - c. the significance of the research to be conducted and potential of researcher.
5. A letter from the dean of the medical school or university sponsoring the applicant stating endorsement of the project.

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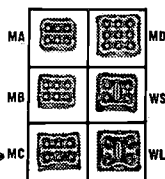
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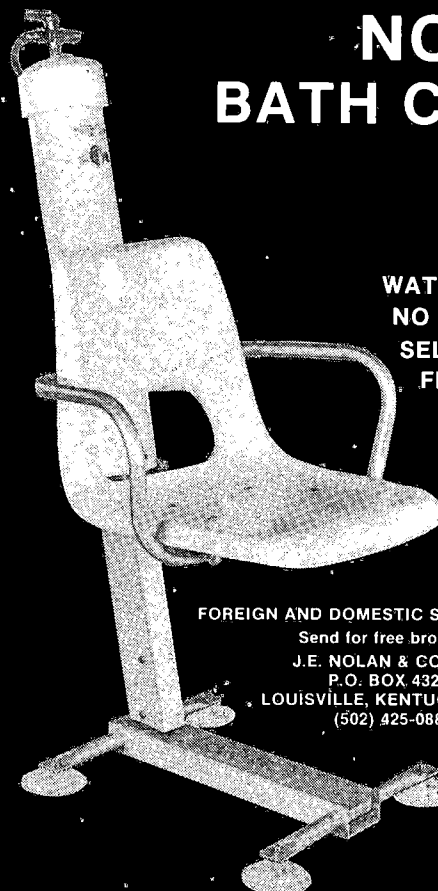


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# Young Researchers from page 38

techniques involving the individual repair of the separate axon bundles within a nerve to avoid the fiber mismatching often found when only the outside covering of the nerve is repaired. A number of recent investigations have questioned the benefits of the more tedious and exacting repair of individual nerve bundles as opposed to the relatively easy stitching together of the entire nerve. These studies, however, were primarily concerned with effects at the site of peripheral nerve repair, such as counts of fibers crossing the injury and conduction of impulses across it.

Brushart wondered if there might be a difference in the appropriateness of the connection coming from the spinal cord to the muscles innervated by these peripheral nerves. Using modern biochemical techniques, he was able to trace individual fibers back to their cell bodies within the spinal cord and was able to demonstrate that the more exacting microsurgery was indeed superior in terms of connecting the motor neurons to the proper muscles. In the process of comparing different types of surgery to the connections in normal animals, Brushart also developed much important new information about the anatomy of motor nerve connections. Moreover, he found that abnormal peripheral connections produced profound alterations in patterns of connections within the central nervous system itself.

Under the Jordan fellowship, Brushart will work in the laboratories of Marcel Mesulam at Harvard University to extend his studies to include sensory nerve repair processes. The immediate implications of this research may be expected to have a profound effect on surgical techniques of peripheral nerve repair. More important, from the standpoint of the goals of the Foundation, the knowledge gained from these studies may be expected to significantly advance basic understandings of control mechanisms in axon regeneration and synaptic patterns in the spinal cord.

## Graham Eric Fagg, Foundation Research Fellow

A \$12,500 Foundation Research Fellowship is awarded to Graham Eric Fagg, age 27. Born in England, he received his B.S. in pharmacology at University of Liverpool and his Ph.D. in pharmacology at University College London in 1976. His doctoral research consisted of a study of amino acid release and uptake in the spinal cord, for which he developed a highly sensitive assay for measuring minute concentrations of amino acids. He continued postdoctoral research at the Max Planck Institut für Experimentelle Medizin in Göttingen, Germany, and at the Universitaire Vaudoise in Lausanne, Switzerland, where he has studied neurochemistry with particular emphasis on the properties of myelin (the fatty substance that surrounds major nerve fibers in the central nervous system) as well as other chemical activities of the central nervous system.

Within the past year, a research group in Sweden reported that nerve fibers in a region of the rat brain known as the hippocampus were able to regenerate and reach their normal target neurons to an extraordinary extent after experimental injury provided that implants of embryonic brain tissue were placed in the cavity formed by the injury. Fagg wishes to follow up on this observation and accordingly will, under this fellowship, work at the University of California at Irvine in the laboratories of Carl W. Cotman, an internationally recognized expert on central nervous system plasticity in general and on the hippocampal formation in particular.

Initial experiments will duplicate and expand upon the Swedish studies with animals. Fagg's work will be done over

continued on page 43

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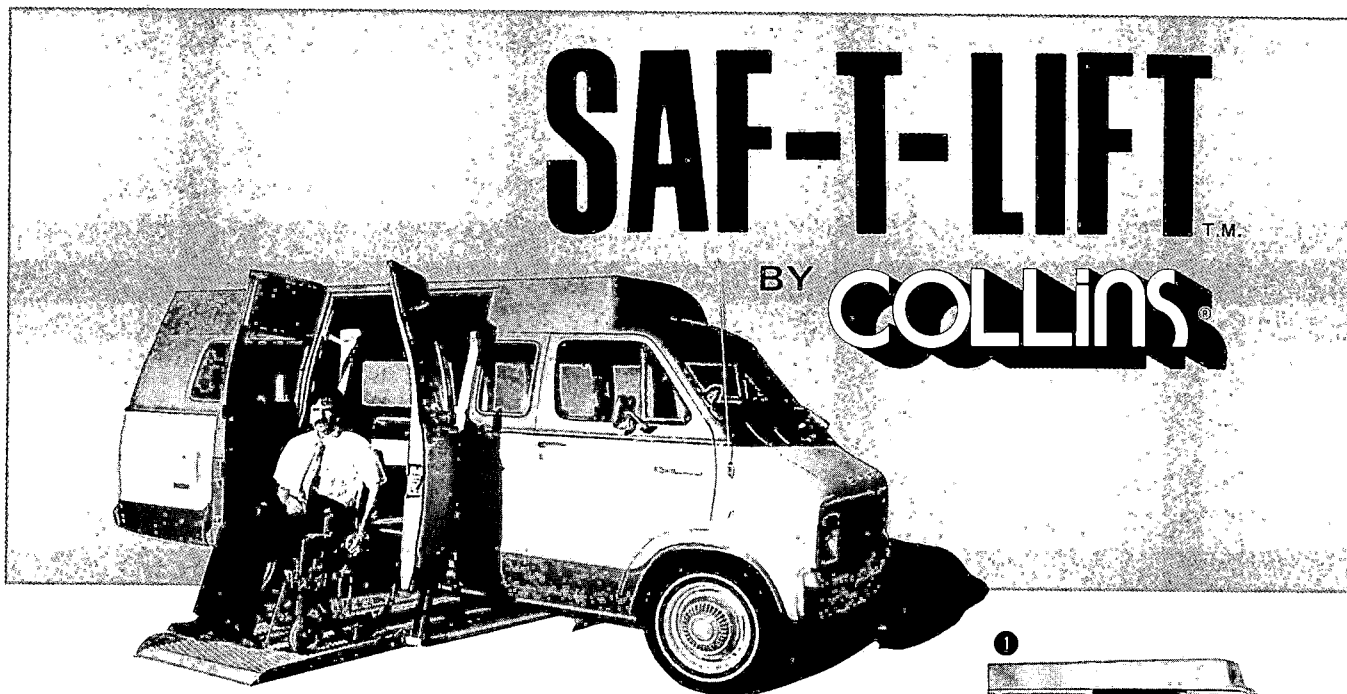
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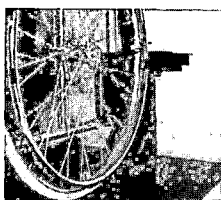
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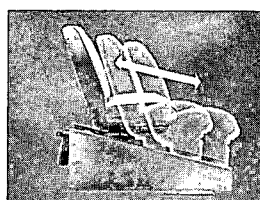
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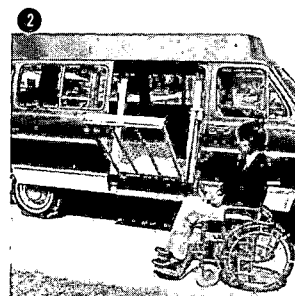
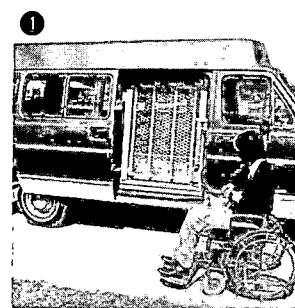


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#### Young Researchers from page 41

longer periods of time and with special attention given to the processes of myelin formation around regeneration fibers. Further studies will be performed to determine whether the mechanical or chemical properties of the implanted embryonic tissue are responsible for the promotion of regeneration. If the latter is the case, Fagg will utilize his biochemical skills to isolate the chemical factor or factors responsible for this growth, characterize their chemical structures, and elucidate their mechanisms of action on the regenerating nerve cells.

#### Marcia Gail Honig, Foundation Research Fellow

A \$12,500 Foundation Fellowship is awarded to Marcia Gail Honig, age 26. Born in New York City, she received her B.A. in biology from Princeton University and her Ph.D in neurobiology from Yale University in 1979. Her dissertation research concerned the mechanisms by which appropriate connections are made during development in the chick embryo. Utilizing the skills acquired in these delicate and painstaking studies, she proposes to complement her background in developmental neurobiology by working on problems of spinal cord organization in adult mammals.

Honig notes that spinal cord transection in humans, cats, and monkeys results in chronic enhancement of reflexes at levels below the lesion, a fact well known by all paraplegics who experience spasticity of the lower limbs. The physiological basis of some of these behavioral changes can be examined in the cat at the level of a single synapse. Electrophysiological techniques have shown that transmission between sensory fibers and motoneurons is enhanced in segments just below the level of transection.

Honig's experiments in the laboratory of Lorne Mendell at Duke University will examine in detail the extent of this synaptic enhancement between various different species of sensory fibers and motoneurons. A major aim of this work is to explain the mechanism or mechanisms responsible for the increase—sprouting of new terminals by sensory fibers being one possibility under examination. A second aim is to determine if the highly specific pattern of connectivity found normally is maintained despite the changes in at least some connections. Additionally, selective partial lesions of the spinal cord will be made to determine whether removal of most input to motoneurons, damage to one branch of the sensory fibers, or a combination of these is responsible for eliciting the changes that result in enhanced synaptic transmission.

This study of a single well-defined system should contribute to our general understanding of the various adjustments that occur in the spinal cord in response to injury and add to basic knowledge of synapse formation and organization that will be required if functional regeneration is to occur.

#### Jeremy B. Tuttle, Foundation Research Fellow

A \$12,500 Foundation Research Fellowship is awarded to Jeremy B. Tuttle, age 31. Born in New York City, he received his A.B. in biology at the University of Rochester and his Ph.D in physiology at Johns Hopkins School of Medicine in 1976. Subsequently, he has performed postdoctoral research in neurobiology at the University of Connecticut. Tuttle notes that the proper function of nerve cells, and even their very survival, depends upon the continual availability and transfer of specific chemical substances among the nerve cells and between them and various tissues of the body with which they make contact. Because of this, profound alterations in the structure and function of nerves follow the interruption of any

of these contacts, such that their normal signalling and regulating duties can no longer be performed. Injury to any part of the nervous system, even mild, thus drastically alters the function of that part, and the alteration may be permanent if the affected cells cannot re-establish the necessary contacts and supply of the sustaining substances.

Very little is known about either the identity or action of these substances or factors. Until recently, only one such candidate substance—known as Nerve Growth Factor—had been identified, and it acts only upon a very limited class of neurons. Attempts to isolate similar substances with actions on different classes of neurons had been in vain until techniques developed in the past few years provided evidence that other such substances with a variety of effects possibly governing all aspects of nerve growth and development do in fact exist. This is a very new and important area of investigation, lying at the very forefront of current regeneration research.

The project proposed by Tuttle is to attempt to isolate and identify another such substance, one that seems to be necessary for the survival of the nerve that controls the muscles of the eye. Both embryonic and adult nerve cells will be removed from laboratory animals and grown under controlled conditions of cell culture. The active survival-sustaining substance or substances will then be isolated by testing purified components of tissue extracts for their ability to support normal growth and function. The electrical, biochemical, and anatomical effects of these substances will be assessed. It is hoped that similar substances may support the survival and function of other nerves that control muscles, and that understanding the dependence of nerve cells upon such factors will aid in the search for ways to stimulate nerves to re-establish their proper connections after an injury. □

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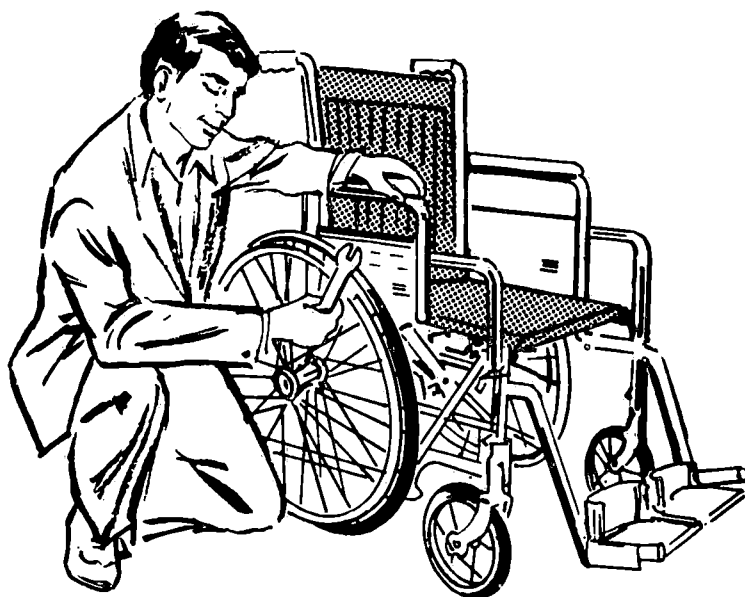
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# A Newcomer's View of the 1979 Wheelchair Marathon

by Jon Barak

with photos by Roland Sharillo

Some of you reading these words would have a difficult time riding a bicycle 26 miles. A larger number might not make it walking. On April 16, 1979, Patriots Day, over 10,000 made it running.

Led by three-time winner Bill Rodgers, who at 2:9:27 broke his own record time for this granddaddy of all marathon races, the 10,000 braved cold winds and a chilling rain over the grueling course from the village of Hopkinton, up Heartbreak Hill, and across the finish line at Boston's Prudential Center. These 10,000 able-bodied athletes participated in this oldest of amateur athletic competitions. And then there were 20 more.

Perhaps it is because Mr. Boston Marathon, Will Cloney of the Boston Athletic Association, has fought against all pressures to keep the race truly an amateur competition that this event has remained so special. Perhaps that is why he gives his support to the group of racers who this year numbered 20.

Well past the five-hour mark, the number of unofficial runners slowed to a trickle. Police began to dismantle the platform where Mayor Kevin White and Governor Edward King placed victory leaves of laurel on the heads of Rodgers and Joan Benoit, who shattered the women's record of 2:42:24 by an incredible margin of seven minutes and nine seconds. The ropes used to channel runners into the proper finishing lanes were gone. The police and volunteers who had done such a fantastic job of keeping the million-plus crowd under control didn't care any longer when people jumped the barricades to congratulate runners personally. My fingers were red and stiff from being wrapped around a metal camera body in the rain for five hours.

I turned to Bruce Marquis, race director for the National Wheelchair Marathon and executive director of the National Spinal Cord Injury Foundation.

"Bruce, do you still think they're coming? Maybe they dropped out because of the cold."

"No, they didn't drop out. You don't know these people. Let's go out on the course and look for them."

We started up the hill and turned right. Bruce shouted at a runner:

"Did you see any wheelchairs back there?"

"There are two someplace," was the reply.

We crossed Newbury Street and turned up Commonwealth Avenue. Three blocks ahead the street was being opened to automobile traffic. It looked like there was a wheelchair there, but it was impossible to tell for sure. There were too many cars.



**"No, they didn't drop out.  
You don't know these people.  
Let's go out on the course  
and look for them."**

Then Robert Darrell Ray of Hollywood, California, via Louisville, Kentucky (Louisville's Distinguished Citizen of 1974), jumped the curb and moved his wheelchair up on the sidewalk, away from the traffic. His left arm was lying limp across his lap. He was struggling to push his chair up the incline with one hand.

Bruce found two motorcycle policemen, who blocked off a lane so Darrell could re-enter the street. They were joined by two foot patrolmen and a squad car that kept the area cordoned off. Suddenly people for whom the 83rd Boston Marathon had become something to talk about over cocktails came to life. They began to cheer wildly.

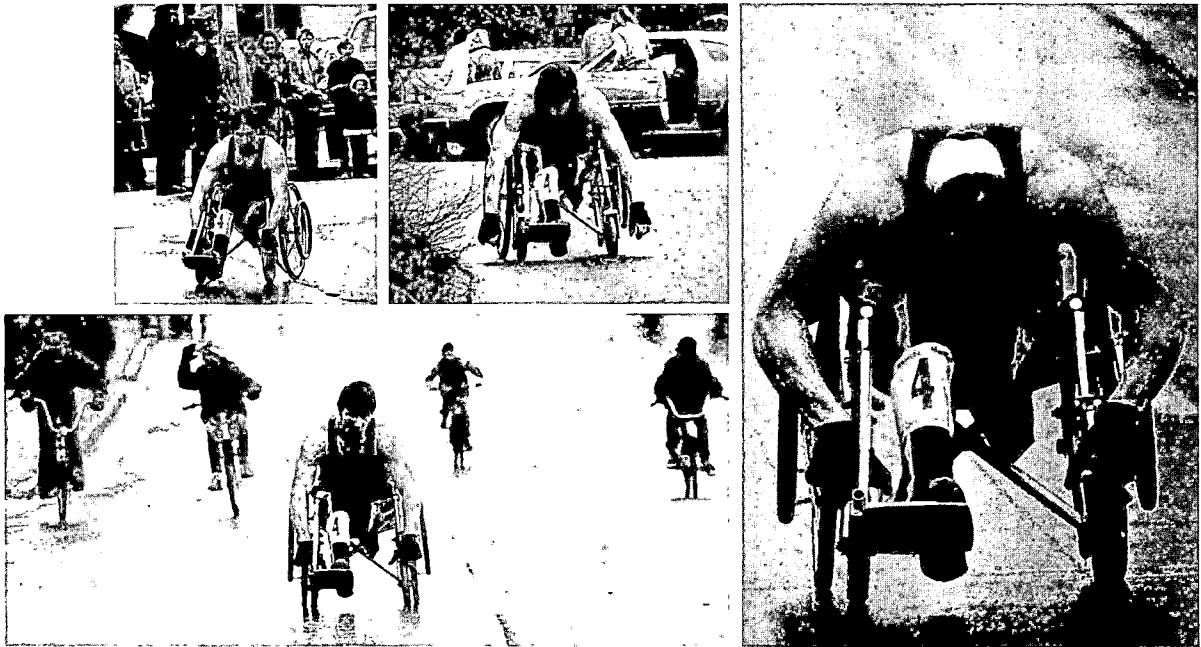
continued on page 47



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**"I participate in wheelchair athletics because I am an athlete. I was an athlete before my accident. . . . now I am a wheelchair athlete."**

#### **Wheelchair Marathon from page 45**

"Atta boy! Keep pushing! You're just about there!"

Windows all along Commonwealth Avenue opened up, and people leaned out cheering Darrell on. Pushing first with one hand and then the other, occasionally with both, Darrell was way past the wall, getting the last ounce of energy from his exhausted body.

Finally, with one last effort, he turned the corner and saw the finish line a quarter of a mile away. Now it was downhill. He could have coasted. After all, what difference does a few seconds make when your time already exceeds five hours?

Darrell didn't come to coast. He came to race, and race he did. Pushing with both hands, he gained speed and crossed the finish line. What the late crowd lacked in numbers it more than made up for with enthusiastic applause.

Robert Darrell Ray was not the first wheelchair racer to cross the finish line of the 83rd Boston Marathon. Kenneth Archer of Akron, Ohio, won with a time of 2:38:59. Sheryl Bair, a dark-haired beauty from Sacramento, California, rolled across with the fastest women's time of 3:27:56.

The weather prevented a repeat of last year's finish, when George Murray, the winner in the wheelchair competition, crossed the finish line ahead of Bill Rodgers, the winning runner. (The wheelchair marathoners begin the race 15 minutes ahead of the runners.)

After the race this year, Murray said:

"There is no doubt in my mind that the next time the marathon is run under ideal weather conditions a wheelchair competitor will clock a faster time than the fastest runner. Last year when I finished ahead of Bill Rodgers I felt like Don Quixote pushing over windmills. I had hoped this year to beat his best time, but there were too many traction problems on the hills because of the rain."

This is the third year wheelchair competitors have raced in the Boston Marathon. In 1975 Bob Hall, a native of Belmont,

Massachusetts, became the first person to push a wheelchair over the marathon distance. In 1977 seven wheelchair athletes entered the race. This year there were over 35 applicants for the 20 positions allowed by the Boston Athletic Association.

A team of five wheelchair competitors wanted to come from Sweden under the auspices of Karsten Inde of Sweden's Rikryterings Gruppen (Organizations for the Disabled). Bruce said:

"When the Swedish group wanted to come and bring Swedish television, it was extremely difficult for me to say no. We hope very much that in the future we can increase the number of participants so that the wheelchair marathon can become an international event. We want the whole world to know that while there are people who because of an accident or disease have disabilities, these people nonetheless are whole and deserving in every way of acceptance by society as complete individuals."

So, who are the people we are talking about? How do we deal with them on an individual basis and within the framework of organized society?

Movie-makers, among others, have grappled with the issues. The Academy-Award-winning film "Coming Home" was, in a variety of ways, a classic encounter with a group of handicapped Vietnam veterans facing the necessity of adjusting their lives to their disabilities. Robert Darrell Ray helped make that film, and I asked him about his experiences.

"It was very illuminating for me," he said, "I was just an extra in the hospital scenes, so I had a great deal of time to sit back and observe the film-making process. I tried to imagine myself doing the jobs of the writers, directors, film editors, technicians, and actors. I watched the interaction between the professional movie-makers and the disabled people working on the film. I began to realize that there were very few in-

continued on page 49

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**"We are all born into bodies in this world. We are all measured by how we use our bodies. . . . Everyone, able-bodied and handicapped alike, has to deal with this."**

#### **Wheelchair Marathon from page 47**

stances in which the disabled could not adapt to a situation and do just as well as the able-bodied. I could see that many of the disabled people would have been able to contribute to any film production, whether or not it had anything to do with disability. Society must stop looking at us as freaks."

I asked Ray why he participates in wheelchair athletics. He answered with a bit of philosophy:

"We are all born into bodies in this world. We are all measured by how we use our bodies. In this society there is an over-emphasis of physical competence and physical beauty. Everyone, able-bodied and handicapped alike, has to deal with this. By participating in wheelchair athletics, I am attacking the problem at its source—not only for myself and other disabled people, but also for everyone else. When I compete in the marathon, I am able to say that I have used my body to its utmost capacity, the same as Bill Rodgers does. There is no difference between us. We are both athletes who have trained hard and gone out and given our best."

The message from all 20 participants in the wheelchair marathon was essentially the same. As one person put it:

"We don't want to be viewed as crippled athletes. We are athletes like all other athletes. We train mentally and physically just as other athletes do. Some athletes play soccer or football. Some climb mountains. We race, play basketball and football, participate in track and field events, lift weights, and do other things while we sit in wheelchairs. There is no difference.

"The Amateur Athletic Union (AAU) and the New York City Marathon have barred wheelchair athletes from participating in their events. They view us as freaks. Shame on them. They should climb into a chair and try to push it 26 miles on a wet day. It might teach them the true significance of competition, if they could finish the course."

Darrell Ray made another pertinent comment in regard to his experience in "Coming Home."

"I watched Jon Voight very closely to see how involved he was with the reality of life in a wheelchair. There were a number of times while he was playing football that he suddenly tipped over backwards. I half expected him to jump to his feet and sit back down in his chair. He didn't. He pulled himself back into the chair the same way I do. Jon Voight knows the wheelchair athlete is just another athlete dealing with the rigors of his sport."

At the marathon victory banquet I listened as person after person spoke with self-assurance and eloquence, from a wheelchair. Why not? Is there anything that dictates a standing position is necessary for eloquence?

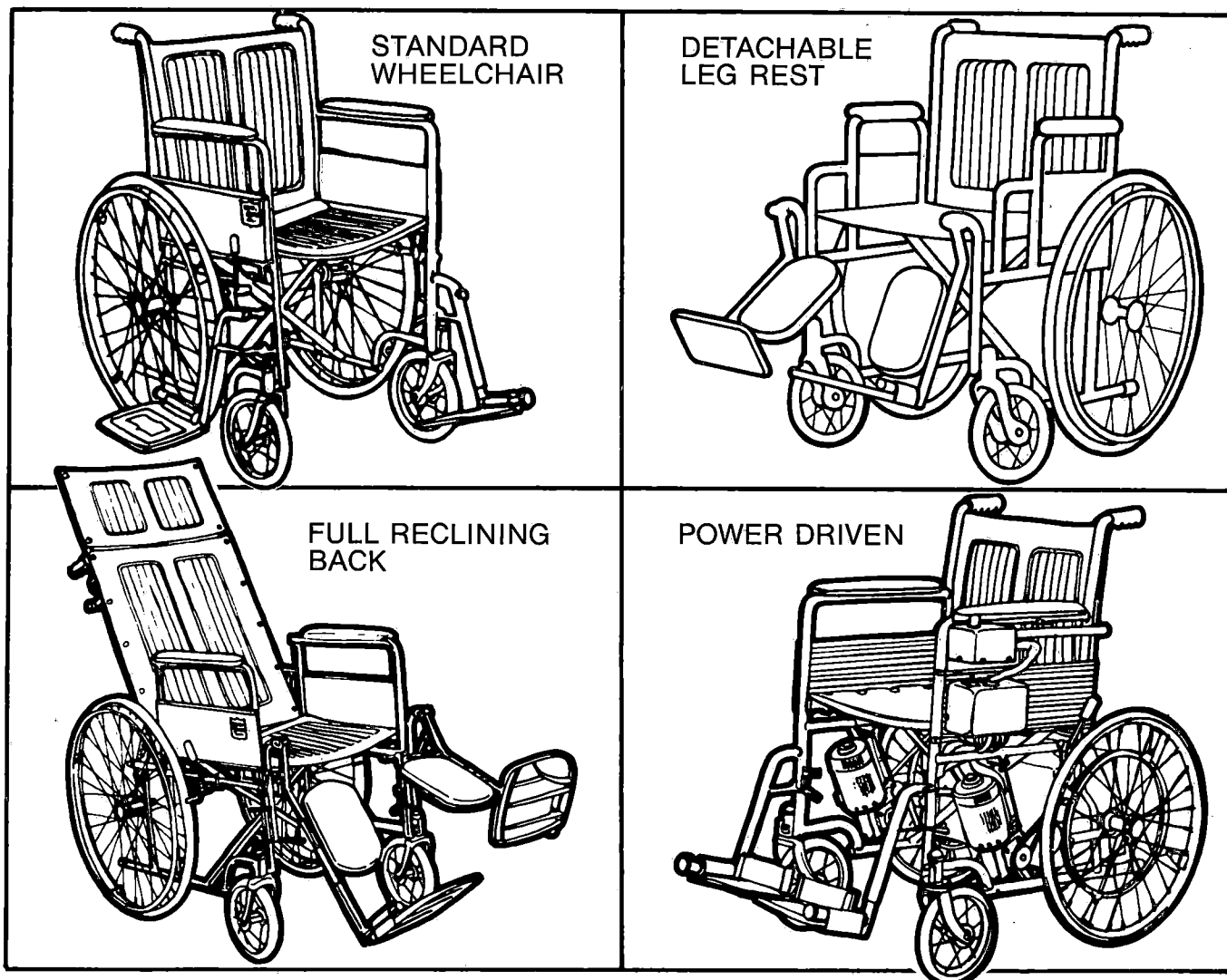
I listened as well-intentioned speaker after well-intentioned speaker stood and talked about the great courage of people who had overcome disabilities to participate in the Boston Marathon. Did the well-intentioned miss the point?

I asked George Murray, "What has participating in wheelchair athletics meant to you in helping you overcome your disability?"

"That is a difficult question, because the words mean so many different things to so many different people. I'll give it to you straight. I have asthma. Marathon racing has helped my asthma tremendously. I am 80 percent improved, but hell, man, I still can't walk. I participate in wheelchair athletics because I am an athlete. I was an athlete before my accident. Since then I have used a wheelchair. Now I am a wheelchair athlete."

I ask you in all seriousness, Who is handicapped? ☐

John Barak is a freelance writer and photographer from Stockholm. An American who grew up in the United States, he has lived in Sweden for more than ten years.



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# Peer Counseling: Process and Goal

by Eric L. Griffin and William Martin

Peer counseling among persons with severe physical disabilities grew from a multifaceted realization on the part of rehabilitation professionals and persons with disabilities that individuals were being institutionalized or kept in dependent environments and behavioral patterns much longer than was right or necessary after experiencing physical loss. It was also recognized that, to a large extent, this was happening because people were not being prepared or were being ill-prepared to live independently in the community. A central aspect was that the professionals comprising the rehabilitation system had not been able to promote positive change and adjustment in several key areas.<sup>1, 2</sup>

Many persons with disabilities can readily recall the incomplete and fragmented nature of their own rehabilitation experiences and the many problems they and their families and friends faced with inordinate difficulty and sometimes disastrous results. At fault were inadequate communication, knowledge, skill development, and support as these persons attempted to formulate coping strategies relative to housing, transportation, personal needs, and the range of other challenges that confront an individual with a severe physical disability who seeks a lifestyle approximating that afforded able-bodied persons in our society. It is not without reason that disabled persons often perceive themselves as lone social fugitives, prisoners of expectations molded by a society that is made uncomfortable by disability.<sup>3</sup>

Perhaps the law of averages dictated that some persons with severe physical disabilities would have opportunities to explore, understand, and act on issues in ways that were effective and that also were very different from those they would have adopted were it not for their disabilities. Through successful response to the challenges of physical disability, many of these persons developed refined and sophisticated understandings of their bodies, diets, and medications as well as service systems, available resources, and other topics related to coping with a disability. These people in time were identified as a needed resource that could be used effectively.<sup>4, 5</sup>

In this context, many thoughtful individuals in the professional community came to a clear understanding that despite unprecedented levels of professional accomplishment, there were still significant shortcomings in the services professionals were providing. There was inability to overcome resistance in "the patient," to close gaps between the individual and the community, and to achieve rehabilitation outcomes consistent with individual needs and choices. As a response, persons with disabilities who were coping successfully were called upon informally to approach other disabled people and share experiences and perceptions. It was thought that

successful disabled people could inspire hope by demonstrating in person the reality of independent and worthwhile lives outside institutions, away from home, and so forth. While this worked imperfectly, it was clearly helpful. Implied in this is the potential ability of peer counseling to reduce threat, enhance communication and self-esteem, and increase coping behavior.<sup>6</sup>

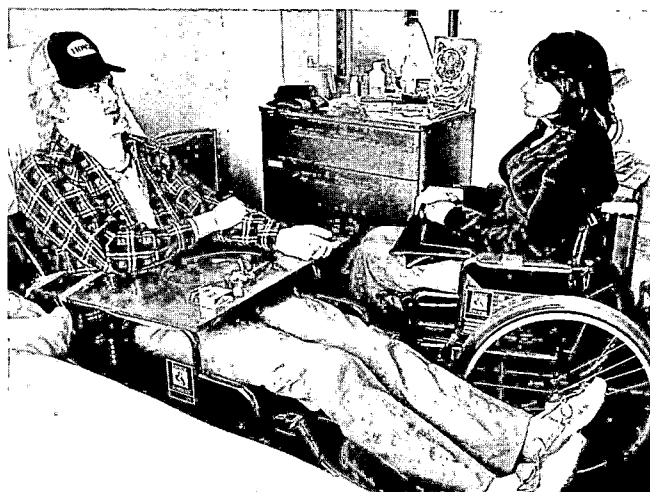
## Significant Questions

Along with recognition of peer counseling as a viable and needed service has come the need to address questions of  
continued on page 53

Photos by Massar



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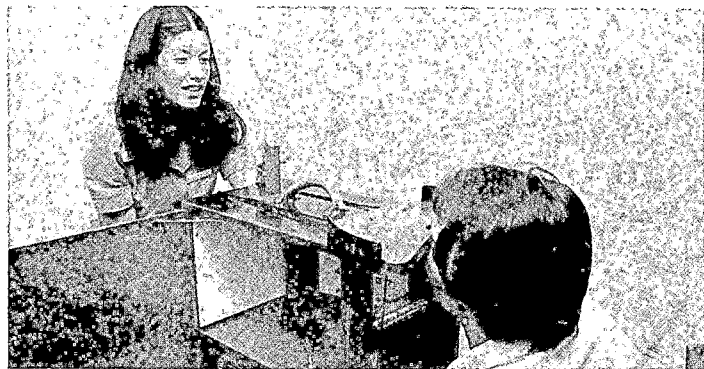
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# **"At what point does the peer counselor tread on professional turf and at what risk?"**

## **Peer Counseling from page 51**

definition, peer counselor preparation and accountability, program development, funding, goals, and limitations. Not the least important question is this: At what point does the peer counselor tread on professional turf and at what risk? Ultimately, the issues are unmet need, effectiveness, and integrity.

This article no doubt will raise more questions than it resolves. Our purpose is to provide a workable definition and conceptual framework for peer counseling and to delineate an approach that is effective, nonprofessional, and conducive to cooperation with professionals. Another purpose is to encourage discussion, understanding, and development of peer counseling services. It is our hope that these activities will be based on a recognition of the nature and critical role of peer counseling in the rehabilitation or habilitation process and also on the need to further validate the effectiveness of one of the most potentially powerful forces that can be brought to bear on behalf of persons who seek greater levels of independence.

## **Control and Management of Time**

An inherent aspect of living in a situation that emphasizes and rewards dependency is loss of decision-making power. Time and the opportunity and ability to decide what to do with that time is a fundamental element of independent living. Persons with disabilities must spend large amounts of time coping with the consequences of disability. How effectively and efficiently one does this determines, to a large extent, the degree to which personal potential is actualized. Ability to control and manage life is directly related to use of time. In a dependency situation the opportunity to determine use of time is altered radically, and the inevitable outcome is that the capacity to use time effectively is eventually corroded. The time frame in which life decisions are made changes along with the manner in which the hours of each day are occupied. The attitude toward time that emerges within the individual may not meet the expectations of professionals, family members, or society at large.

The peer counselor, however, is someone who has experienced these detours in the life process, these alterations of time as it applies to day-to-day activities and life decision-making. Unlike an able-bodied professional, the disabled person sees a taller world going by at a fast pace, watches it climb stairs, knows that it does not have to face many of the frustrations and attitudes that the peer counselor and the peer client face individually and collectively. A peer counselor is uniquely qualified to empathize with the peer client and respond appropriately to his or her concerns. A peer counselor can be identified as a resource by someone who feels guilty or shameful or angry or depressed because he or she is not living up to society's expectations.

Disability can become an excuse for escape, but a peer counselor can help a disabled person differentiate between time altered and responsibilities avoided. Through a counseling relationship in which peers can identify with each other, threat can be reduced, and an emotionally supportive mutual respect can be established. An individual can explore and understand problems and still live life in consonance with his or her own time frame. This provides the basis for acceptance

of where and who one is and the understanding necessary to assume responsibility for coping effectively through a process of self-determined actions.

## **Individual Feelings, Values, and Needs**

Persons who need and desire peer counseling come to the situation with a wide range of feelings, values, and needs. For example, some are confident and energetic and will need only information. Others experience significant and painful deficits that contribute to their dependence. In either case, the peer counselor can facilitate independence by providing practical information and assistance in acquisition and application of problem-solving skills.

The peer counselor also can interrupt patterns in the environment that encourage dependence and feelings of helplessness. Very often persons with severe physical disabilities attract people because of their needs and complaints. This can result in commitment to maintenance of needs and avoidance of problems and risks. The situation is confounded by lack of knowledge about available resources and alternatives.

Ironically, needs and complaints attract peer counselors just as they attract others who wish to be helpful. The peer counselor, however, has a different perspective than physicians, nurses, social workers, counselors, therapists, and the like. The peer counselor can accept the peer client's frame of reference as the focal point of activities and interactions. There is no attempt to impose professional, institutional, or agency values.

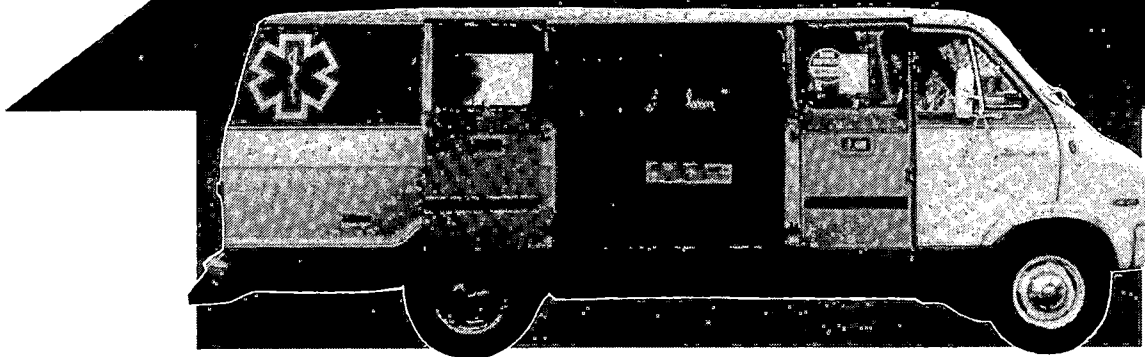
For the peer counselor the initial objective is establishment of a relationship that can serve as the basis for exploration and definition of problems. The process of relationship-building is predicated upon acceptance of the peer client's value system and an empathetic, respectful, and appropriate level of response to the emotional and factual content of individual perceptions. The organizing principle for this dialogue should be self-management on the part of the peer client. In this context, helping the individual becomes a matter of identifying problems and formulating strategies that assist problem resolution, acquisition of problem-solving skills, and increased levels of responsibility, self-management, and independence.

## **The Source of Control: Why Me?**

Individuals who have a history of dependence and failing often do not view their behavior as causal. For this reason, many people the peer counselor meets do not see their own behavior as a controlling factor in their lives. They have come, perhaps as an adaptive response to harsh realities, to view the external environment as the source and determinant of rewards, successes, punishments, and failure.<sup>7</sup> For many this perception predates disability and may have been a contributing factor in reactions to disability such as those characterized by notions that paralysis is punishment for sins. For such persons success may come slowly, because the idea of self-management is so alien. The peer counselor may help most simply by following up on mutually agreed upon and carefully measured steps toward defined goals. This is not trivial. Even modest successes may encourage the individual

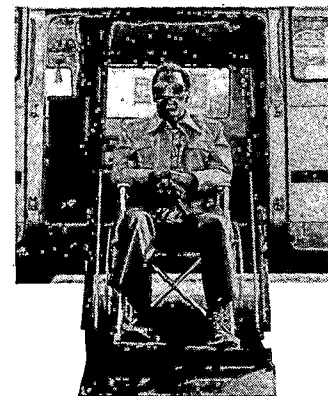
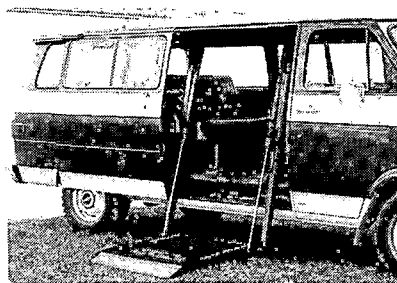
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**"Unlike an able-bodied professional, the disabled person sees a taller world going by at a fast pace, watches it climb stairs, knows that it does not have to face many of the frustrations and attitudes that the peer counselor and the peer client face individually and collectively."**

**Peer Counseling** from page 53

to shift his or her perceived source of control from the environment to the self.

### **Ongoing Assessment**

The peer counselor must be able to facilitate personal change and adjustment by developing a bond with the peer client focused on the issue of self-management. Ongoing assessment of progress, strategies, feelings, values, and resources is a necessity. Of first importance is time and how it is used, and within this frame of reference there must be physical, environmental, emotional, and intellectual assessment.

Generally speaking, time should be considered in terms of how much is needed, how it is used, and how it can be used better. Specific issues might include time for getting up, toileting, dressing, eating, transfers, and transportation. How is time used during the day, and what does this use of time indicate about the individual's dependence or independence? What tense does the person live in? Does he or she recall the past constantly, fantasize unrealistically about the future, or live in the present, face problems, and plan for the future? Individual perceptions play a critical role. The way a person uses time or thinks of what to do with it is strongly influenced not only by physical disability but also by awareness of capacities, potentials, resources, and alternatives.

**Physical assessment** — This includes a range of specifics: available motions, medications, skin care, bowel and bladder function, and sexual function, for example. The more information and knowledge one has, the more likely he or she is to be able and committed to achieve increased levels of independence. For this reason, it is important to address assets and deficits in knowledge as well as specific functional capacities and limitations. Body image also is significant. It can enhance or further restrict interaction with the physical and social environment.

**Environmental assessment** — Like anyone else, a person with a severe physical disability interacts with the environment in many ways. However, disability raises questions that can be disheartening. For example, to what degree does the environment grant access? For someone whose mobility has only recently been impaired, this is far from obvious. Similarly, a person who has spent years in a protected or artificial environment may have no meaningful experience coping with community environments that are less than ideal.

Beyond the fairly straightforward task of learning what is available to enhance mobility and how to cope without what is not, comes the much more difficult matter of learning to live in the community environment in a satisfying way. The person with a severe physical disability must assess in some detail the availability of housing, transportation, recreation, employment, medical facilities, social services, commercial establishments, and so forth. The social environment also deserves attention. It is helpful for the individual to develop a practical understanding of the attitudinal barriers that play

unnecessary and counterproductive roles in many situations.

**Emotional assessment** — Critical in this area are the individual's reaction to disability and the importance of clarifying values. The reaction will appear in many forms and is seldom all positive or all negative in nature or implications. Nevertheless, the individual must explore and define the problems and obstacles that arise within as well as those posed by the external environment. This often is the key to effective coping instead of succumbing.

The task is to assess and be explicit about values and beliefs and to explore ways these values and beliefs can enhance or limit emotional life. For example, sexual values usually must be realigned after onset of disability. Similarly, values surrounding body image must be changed to accommodate physical loss. The possibilities are limitless. Specific issues will emerge in a problem-solving atmosphere that openly takes into account needs and their relationship to personal assets and deficits.

**Intellectual assessment** — There are clear relationships among ability to approach and cope effectively with problems, knowledge and gaps in knowledge, and potential for self-management and independence. The task is to assess strengths and weaknesses in knowledge and skill and to formulate specific means of responding to needs.

Assessment is an ongoing part of problem-solving. One of the skills of living independently is self-monitoring. The peer client should be actively involved in initial and later assessments of his or her situation, not only to gain knowledge but also to develop the habit of self-assessing and self-monitoring.

### **Who and What Is a Peer Counselor**

Peer counselors usually have similar backgrounds. They experience permanent physical loss and limitations, and they demonstrate ability to cope with challenges effectively. What separates them from their peer clients is that

- they have expressed their desire to assist others achieve optimal growth and adjustment,
- they have prepared themselves for this role by undergoing training, and
- they have committed themselves to peer counseling in theory and practice.

Most counselors seek personal growth and realize that their own growth will be enhanced by their work to promote the growth of others. Each peer client becomes an echo of the counselor, reminding the counselor of issues resolved and tasks left unfinished. Thus, the word *peer* implies not only a common personal history but also a simultaneous and mutual effort to grow and further self-management and independence. The counselor and the client share and refine the problem-solving process.

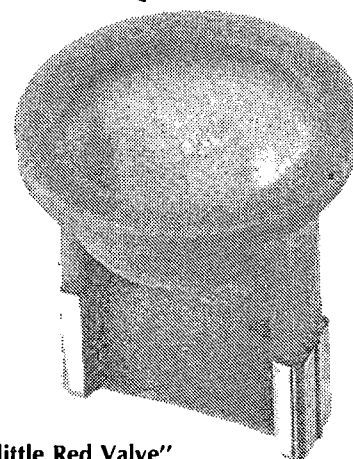
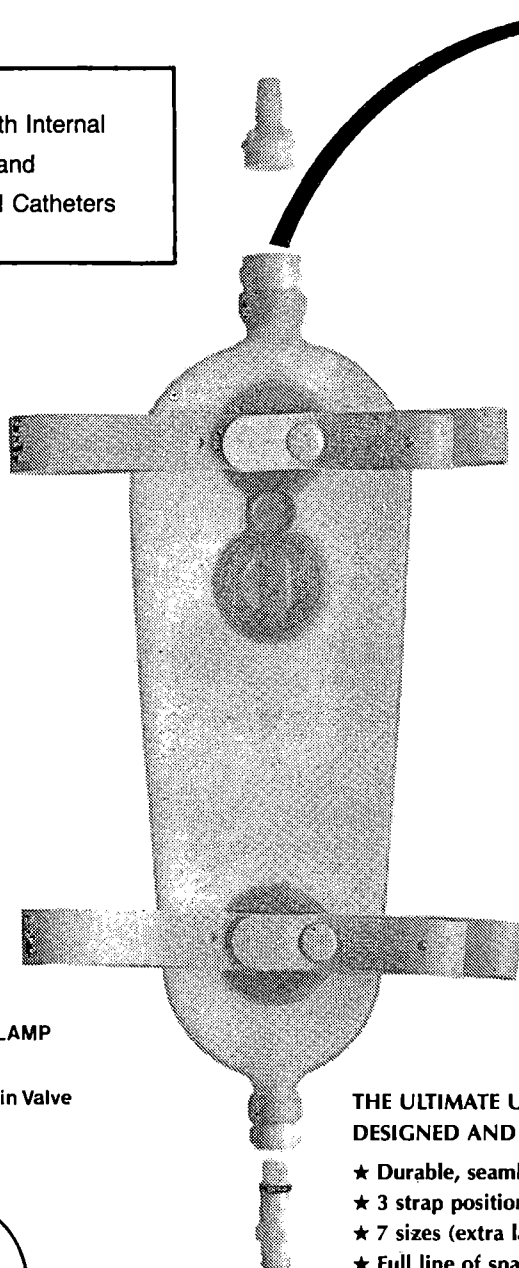
A number of approaches have proved effective: one-to-one counseling, problem-solving groups in which one or more persons facilitate interaction, role modeling, selective utiliza-

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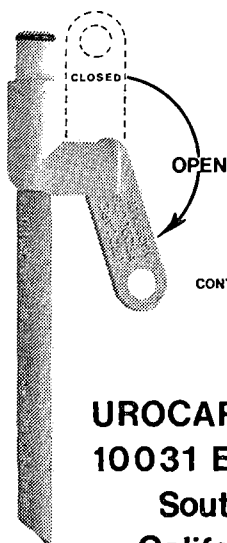
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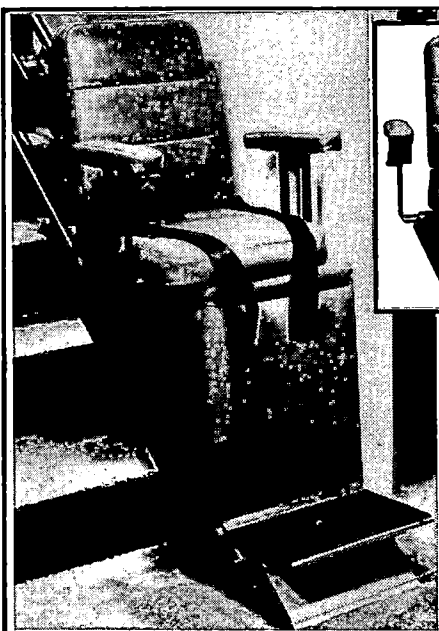
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#### Peer Counseling from page 55

tion of a disabled person to accomplish a specific task, workshops, and just living life with some feedback from caring peers.

Since the goal is to help people reach the point where they are self-managing, the peer counselor has the opportunity to be both a co-advocate and a co-manager. Co-advocacy emphasizes mutual identification in a cooperative effort to secure services and rights needed by all disabled people. Here the peer counselor both teaches and refines advocacy skills. In co-management the counselor enters group meetings such as discharge planning conferences in order to ensure not only that the peer client has input but also that he or she manages the meetings as much as possible, since they relate most directly to the client's life. In such meetings the counselor supports the client and helps reduce the threat professionals may feel in the face of self-assertion by a patient/client.

The peer counselor is a resource for professionals, not only in the rehabilitation establishment but also in the community at large. Professionals with whom the counselor may work include occupational therapists, social workers, educators, and specialists such as housing authorities and architects.

People who are being counseled often become candidates for employment as peer counselors. These individuals grow through their involvement in peer counseling and show traits that indicate they would be good counselors. It is important to realize that people can be used selectively as peer counselors or role models and that someone who lives in an institution and is very dependent may nonetheless have skills or attributes that could be shared. This sharing would enlarge self-esteem and be part of the individual's growth process.

#### Program Structure and Leadership

Many approaches to peer counseling have been and are being employed, and it is important that new methods be encouraged. Examples include:

- *Institutional setting* — The peer counselor receives referrals from the staff of the institution, works with "patients," and reports to the staff of the institution.
- *Independent living program* — This parallels the case management approach. The peer counselor works as a staff member for the program, meets peer clients and other staff regularly under supervision, and functions in a range of ancillary activities.

continued on page 59

**"The peer client should be actively involved in initial and later assessments of his or her situation, not only to gain knowledge but also to develop the habit of self-assessing and self-monitoring."**

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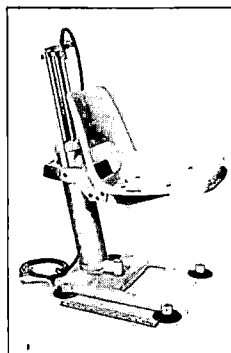
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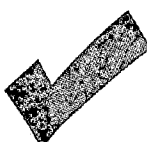
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**"... the word 'peer' implies not only a common personal history but also a simultaneous and mutual effort to grow and further self-management and independence. The counselor and the client share and refine the problem-solving process."**

#### **Peer Counseling from page 57**

- *Pyramid* — Peer counselors train peers to become peer counselors who in turn train others.
- *Groups* — Multiple role models assist a process in which the peer counselor serves as facilitator in a collective atmosphere of assessment and problem-solving.

The structure of peer counseling programs emerges from the circumstances and the philosophies of those involved. Structure, which can take many forms, implies leadership, which can mean many things. Structure allows timely response to referrals, regular and responsible contact with peer clients, communication with rehabilitation and community professionals, effective decision-making, and refinement of services. Leadership facilitates these processes and addresses the education of the workers and the survival of the program.

If a program anticipates payment for peer counseling services, documentation is necessary to indicate what work is being done, what results are being obtained, and what additional resources are needed. Documentation also is an important part of problem-solving. Problems and proposed solutions are clearly stated and can be referred to. Over time, documentation indicates patterns of progress and needs not yet addressed.

Structure and leadership are central issues in peer counseling. The test of structure is its adequacy in dealing with assessment and problem-solving in a timely way.

#### **Training Programs To Acquire and Impart Skills**

Training promotes personal effectiveness. Training formats include workshops, conferences, academic courses, on-the-job training, and in-service speakers. Topics of particular importance to peer counselors include:

- assessment skills;
- interviewing techniques;
- understanding the problem-solving process;
- understanding group processes;
- understanding resources (agencies and their processes, SSI/SSDI, medicaid/medicare, housing, personal care services, transportation, medical services, medical supplies, etc.);
- understanding disabilities.

As an example, to refine environmental assessment skills a workshop could be co-produced by a group of peer counselors and occupational therapists in order to educate each other about assessment from two different perspectives. If peer counselors take responsibility for organizing such a training program there are direct and secondary gains:

- they refine their peer counseling abilities;
- they develop good work habits and marketable skills;
- they have positive influence on the skills and attitudes of rehabilitation professionals; and
- they gain greater awareness and respect from the community at large.

Each peer counselor who takes responsibility develops his or her own skills by learning how to produce workshops.

Similarly, peer clients can take responsibility for establishing their own skills training programs.

#### **Conclusion: Invitation To Continue Discussion**

Ending this article is difficult because peer counseling is in such a preliminary phase of development. There is need for much more discussion by the peer counseling constituency and a collective effort to define, refine, and promote peer counseling as a viable component of existing service systems.

The journey from the present to some future time when peer counseling is an effective and widely available resource inevitably will involve detours around faulty reasoning and professional potholes. There are misunderstandings to overcome, but there is also a sound base of favorable research and experience. This, along with ongoing commitment to peer counseling and the rehabilitation process, should assure genuine progress toward clarity and acceptance.

In closing, in all fairness, we should point out some deficiencies in this article. We have only implicitly addressed the issue of funding for peer counseling programs, and we have said little about program development and peer counseling training. With respect to the latter, we plead guilty because there is too little space; with respect to the former, because situations and environments are so diverse in various parts of the country that it is difficult to predict what will or will not work.

It was our intent that this article be meaningful to all concerned with the interlocking issues of self-determination and independence for persons with severe disabilities. To be comprehensive, we have sacrificed some of the focus that would have been possible if we had targeted a particular audience—for example, consumers or professionals. Be that as it may, we hope that we have identified issues to be considered and that we will have the opportunity to be a part of an ongoing discussion. □

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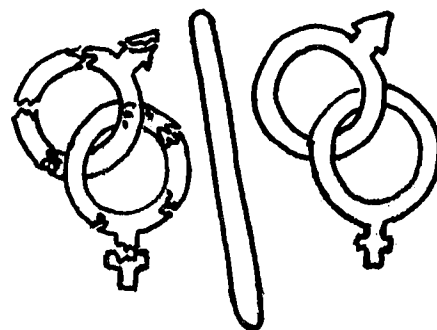
The authors are staff members of the National Spinal Cord Injury Foundation. Eric L. Griffin is program coordinator for the Southeastern Massachusetts Independent Living Rehabilitation Program based in Lakeville, Massachusetts. William Martin is program director for the Northeastern Massachusetts Independent Living Rehabilitation Program based in Lawrence, Massachusetts.



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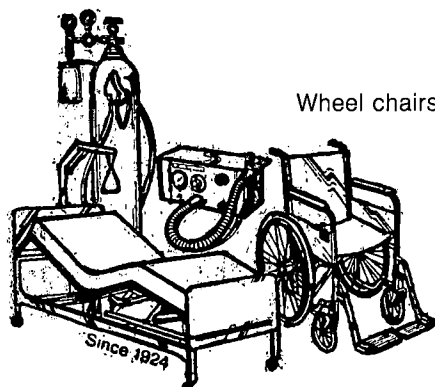
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**Ellen Hollister is a student at the University of California at Davis. She's also in a wheelchair, the result of an automobile accident that caused permanent spinal injuries.**

**"I chose my college carefully. Davis is one of the best campuses for disabled students," Ellen explains. "I've memorized its network of ramps, I know where the building elevators are and what special classroom equipment there is. Then, too, there are the offices of Services to Handicapped Students that personify expertise," she says. "They encourage you to follow your interests. For example, they are responsible for an adjustable bench in the chemistry lab so that wheelchair students can participate in the lab aspects of the course. Their counseling services are also very supportive." Ellen's interest is the same as any college woman's but it is complicated by the demands of a wheelchair. "I've learned what works for both of us," she says. On these two pages, you see just how well she's succeeded.**



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**The chair sets limits** "The chair is all the bulk I want, so simplicity is the key word for me. I watch what happens to attractive clothes on my friends when they sit down. When I see a lot of wrinkles and excess material, I steer clear of that style. Neatness is synonymous with simplicity. Pants offer a more unified look—not as many wrinkles. I wear them even for formal occasions. The cut of the pants is important. If you can't cross your legs, the thighs spread a lot, and the pants have to allow for this and yet not be too big and sloppy-looking. I'm inclined to have the legs taken in a bit to let the cut help support me, make up for lack of muscle tone, though medical authorities warn that you must watch out for skin irritations and circulation problems."



**Easy dressing** "Pullovers or loose cowlnecks are easy to get on and much neater-looking than cardigans which tend to bunch up when sitting. Cardigans also tend to gap between the buttons. A sweater worn with pants makes a good-looking, dependable everyday look for me. I usually buy my pants about 4" longer than necessary so that my ankles are covered when sitting. If I do wear a skirt, rather than pants, I like boots. They give a nice line, a uniform look and they hide swollen ankles. Clogs with backs are good, too. For dressy occasions, I usually wear pants, but the really dressy ones often have wide legs and they are a problem. They look floppy and wrinkly in the chair. If I can't find what I want in pants, I wear a long dress (*below*) which looks smooth and attractive."



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- Jewelry is best kept to a minimum. Too much, or anything too fussy, makes you look cluttered.
- A short coat or a down vest is good for cold weather. They're both warm, but not bulky around the hips.
- A poncho with a hood is good for rainy days.
- Watch out for clothes with back seaming, pockets or zippers. They can be a problem: Even if you have no pain sensation, they can cause skin irritations.
- A front-hook bra makes life much simpler.
- A wrap-around garter belt and regular stockings are easier than pantyhose.
- Always pick clothes with the main interest on top — say, a pretty V-neck or a cowlneck.
- Pay more attention to your hands and neck — that's where people's attention tends to focus. Polish on nails, if not too dark, can be attractive.

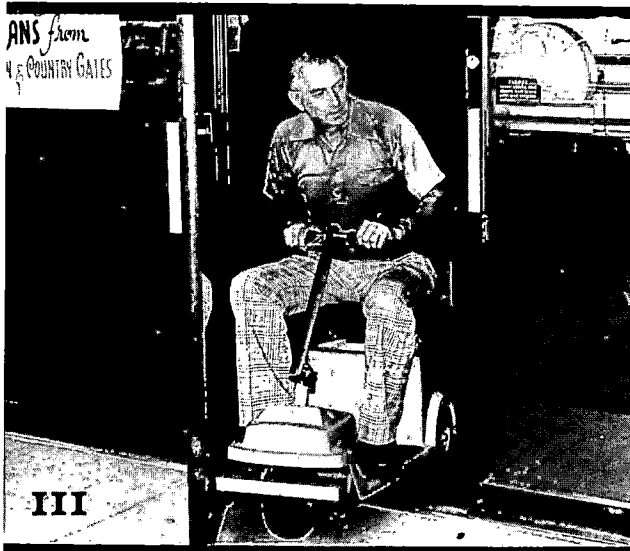


**Ellen's handbag solution:** She uses a large saddlebag style hung over the back of the chair. This keeps it out of her way, yet accessible when she needs it.

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# Independent Living Programs: A Network of Resources

by David R. Williamson

Increasingly, disabled people are emerging as a new minority asserting their claim in the housing market. In response to their pleas, there is a rising level of awareness of the rights of the disabled and a growing effort to meet their needs, including the need for affordable community-based housing.

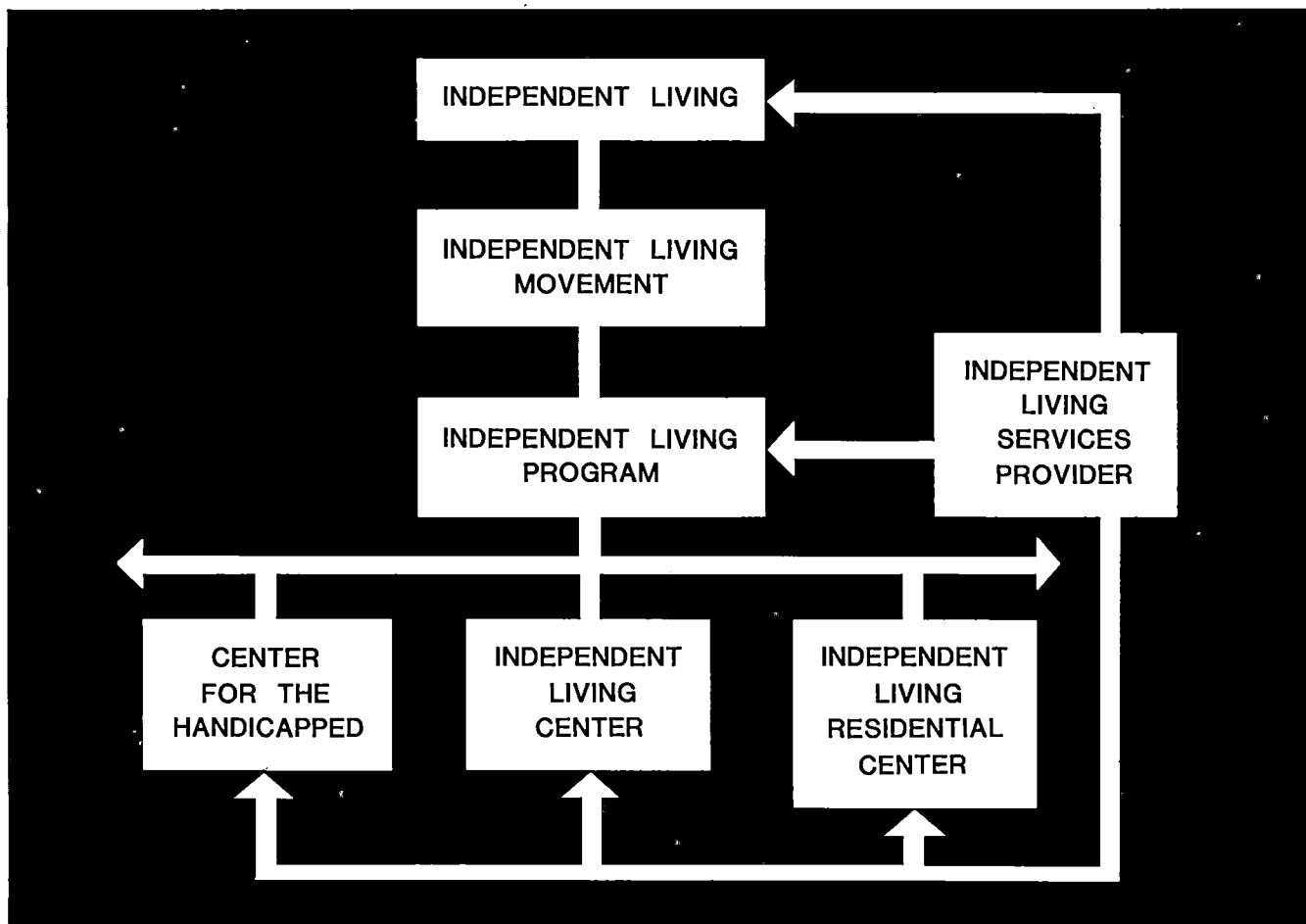
It is not enough for disabled people merely to declare their independence—they must first begin to free themselves of the architectural, communication, and attitudinal barriers that imprison them; and, depending upon their disability, they must assemble a network of resources to survive independently.

Groups of disabled persons have committed themselves to raising the public awareness of their needs and taking action to satisfy these needs. This has resulted in a national Independent Living Movement.

As shown in the diagram on this page, the Independent Living Movement encompasses the concept of independent living and is realized through three major programs: Centers for the Handicapped, Centers for Independent Living, and Independent Living Residential Centers. Each of the latter relies upon tapping a network of resources, and each aims at

continued on page 67

## Diagram of Independent Living Concepts & Organizations\*



\*Texas Institute for Rehabilitation and Research, "Definitions Related to the Concept of Independent Living," unpublished paper, p. 7, 1978.

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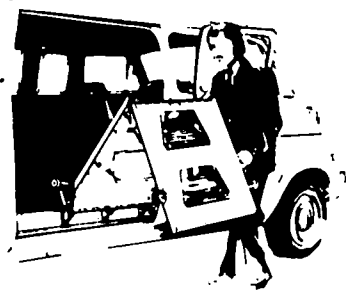
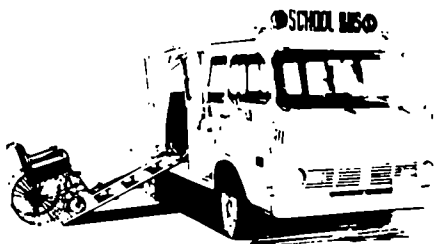


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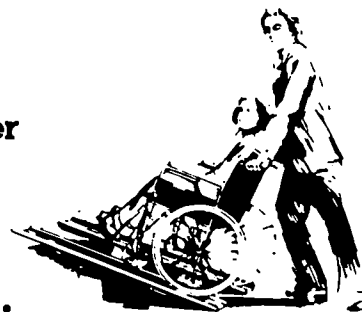
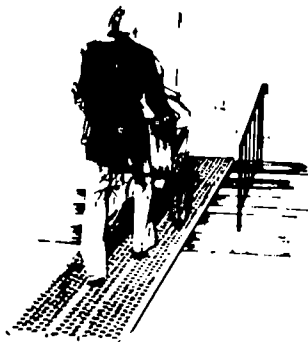


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**"To grow up with their siblings, to get an education, to hold a job, to raise a family and share in the joys and responsibilities of community life are hopeless dreams unless suitable housing is available."**

**Independent Living** from page 65

normalization, mainstreaming, and integration of the disabled into the community.

### **Recent History**

The Independent Living Movement has been gaining momentum in the United States since the early 1970's. Its stated goal is realization of basic human rights by reducing and eliminating the physical and social barriers that prohibit the disabled from actively participating in society. The movement is based upon a broad concept of independent living that includes the network of resources allowing an individual full participation in society despite functional limitations and enabling the disabled person to experience greater control over life.

The Independent Living Movement emerged from a combination of interacting factors: the end of the Vietnam War sending home thousands of paralyzed veterans; deinstitutionalization by the states returning to the community thousands of persons capable of living independently if afforded a supportive environment; and the anger and frustration of disabled people as a group who for so long had been treated as second class citizens. These pressures had been building in a society that had no grasp of the problem, much less a coordinated service delivery mechanism to cope with the problem.

### **Centers for Independent Living**

The first Center for Independent Living, the Berkeley CIL, was established as a self-help outreach program designed to expand options and alternatives available to disabled people. The center provides a variety of services such as family and peer counseling, mobility training, housing assistance, wheelchair repair, and attendant referral and training. Since 1972, over 30 Centers for Independent Living have been created across the country using the Berkeley CIL as a model. Although no two centers are identical, a Center for Independent Living can be generally defined as an independent living program that is nonprofit, consumer-operated, and nonresidential in nature and that provides a specific set of services.\*

Different goals, philosophies, funding sources, and organizational structures make each center unique. There are, however, two basic commonalities that all centers share. First, the purpose of each CIL is to help disabled individuals live independently in the community rather than dependently in institutions. Second, each center functions with extensive consumer involvement and control so that people with disabilities have the opportunity to plan and implement the decisions that affect their lives.

### **Other Independent Living Programs**

A Center for Independent Living is only one of three major vehicles disabled people can use to achieve an independent life. The others are Centers for the Handicapped and Inde-

pendent Living Residential Centers, both of which are community-based programs that provide coordination with and referral to existing services or provide new services to help severely disabled individuals increase self-determination and reduce unnecessary dependence upon others. Currently, it is estimated there are over 450 Independent Living Programs in one form or another throughout the United States.

A Center for the Handicapped is a single- or multi-purpose facility that seeks to assist persons with disabilities become more functional members of the community by providing such programs and services as recreation, education, health care, social development, independent living, and physical and vocational rehabilitation. By using service mechanisms already in place, such a center can coordinate the delivery of services to the disabled through referral and advocacy.

An Independent Living Residential Center *directly provides* housing, attendant care, and transportation, rather than offering referral to these services.

### **Housing Problems, Options, and Resources**

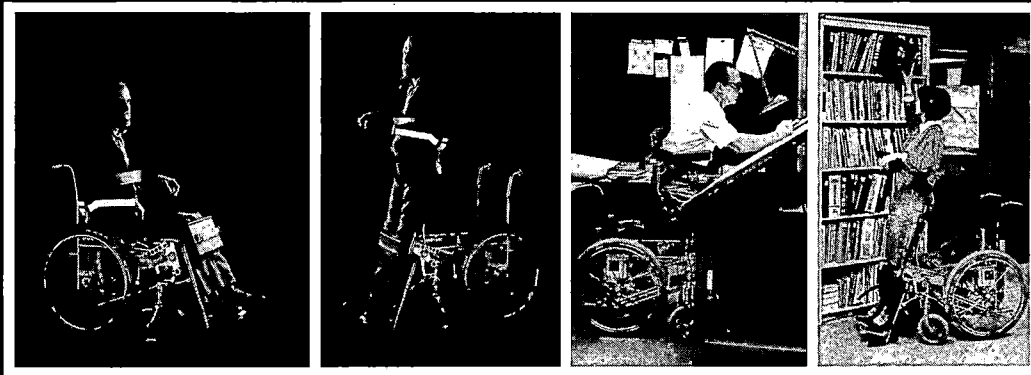
Housing alternatives are an integral element in the comprehensive independent living service delivery system. Today many disabled individuals who might be capable of functioning independently are instead forced to live in nursing homes and large institutions because of the lack of accessible and affordable community-based housing. The need is for many different types of housing ranging from small group homes offering support services to single-family dwellings to barrier-free units in ordinary apartment buildings.

The lack of good housing in the right location can hamper independent living even if other services are available. For many disabled people the prospects for acquiring good housing in the right place have been dismal. Such individuals not only find themselves in a housing predicament, they also find themselves with precious little chance of escaping that predicament. To grow up with their siblings, to get an education, to hold a job, to raise a family and share in the joys and responsibilities of community life are hopeless dreams unless suitable housing is available.

The word disability encompasses a variety of handicapping conditions, and no one type of housing would be suitable for all disabled persons. Different housing alternatives have evolved to meet the needs of persons with different disabilities. A person's age, family status, type and extent of disability, and desired lifestyle influence his or her choice of the most appropriate living arrangement. A physically disabled person might get by with a barrier-free dwelling in an ordinary apartment building, whereas a severely mentally disabled person might need a group living situation with support services including training in the skills necessary for independence.

Provision of adequate housing and support services is hampered by a number of circumstances, many of which must be addressed at the national level. It is unreasonable to

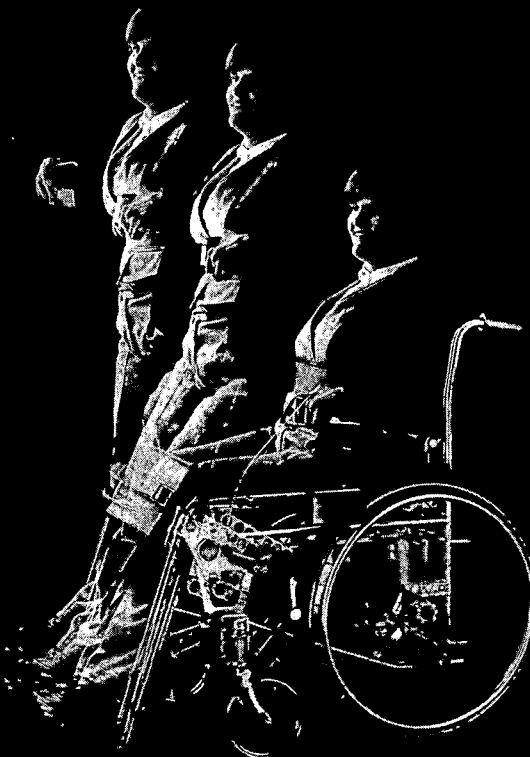
\*Driscoll, J.V. Second Generation: New England, *American Rehabilitation*, 1978, 3, p. 18.



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## Independent Living from page 67

expect states and local communities to bring together all the necessary resources for independent living programs and suitable housing for the disabled without the support of articulate and well-planned Federal objectives. These must be supplied by the Department of Health Education and Welfare (HEW) and the Department of Housing and Urban Development (HUD).

### A Look at HUD

At HUD, the Office of Independent Living for the Disabled (OILD) is the focal point for policies and programs that are helping to alleviate the housing crisis confronting the disabled population. HUD's goal is to integrate the disabled with the rest of society by providing a variety of housing options and resources. This goal mirrors those of Centers for Independent Living and Independent Living Programs. HUD aims to achieve this goal by redirecting existing programs mandated by Congress to meet the needs of the disabled, or when this is not workable, by creating new programs. Some of HUD's activities over the past 18 months include:

**Barrier-free percentage requirements** — In late 1977, HUD Secretary Patricia Roberts Harris decreed that for new family housing funded under HUD's Public Housing and Section 8 Rental Assistance Programs at least five percent of the dwelling units must be barrier-free. These units are to be integrated throughout the housing project, and the types of units are to be varied among efficiencies, one-bedroom, two-bedroom, etc. in the same proportion as such types are distributed throughout the entire project. Previous to this policy-setting statement, percentage requirements at HUD had applied only to housing for the elderly, not to family housing.

**Section 8 rent subsidies for group residences** — During the past year, HUD issued final regulations making Section 8 rent subsidies available to persons with disabilities who live in group homes. Previously, such subsidies, which ensure that the resident pays no more than a fourth of monthly income for rent, were not available to the residents of group homes. The Section 8 subsidy can only be used for rent, so the cost of needed support services must be covered in some other way.

**The disabled made part of housing assistance plans** — For many of HUD's programs, the dispersal of funds is contingent upon a Housing Assistance Plan (HAP) that sets forth the housing needs of each community and its priorities for meeting these needs. In the past, the needs of the nonelderly handicapped were not treated separately in Housing Assistance Plans but instead were lumped with the needs of the elderly. The upshot in many communities was that the needs of the elderly were met, but the needs of the nonelderly handicapped were not.

In October 1978, HUD issued new regulations encouraging communities to prepare separate narratives on the housing needs of the two groups and to set separate goals for achieving these needs. HUD has also worked with the National Bureau of Census and other information agencies to see to it that data are gathered separately for the nonelderly handicapped and the elderly. In this way the facts about both groups will be set out, and both groups will benefit from more accurate representation. Explicit data will help communities prepare their Housing Assistance Plans.

**Section 202 program** — In this program, designed to develop housing for the handicapped and elderly, HUD Section 202 funds provide low-interest mortgage money to construct or rehabilitate group homes or residential independent living complexes. These loans often are accompanied by Section 8

continued on page 71

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**"The upshot in many communities was that the needs of the elderly were met, but the needs of the nonelderly handicapped were not."**

**Independent Living** from page 69

subsidies that provide direct assistance to elderly and disabled tenants in meeting their rental payments. These rental payments in turn help pay off the Section 202 loan mortgage.

Until recently, program sponsors for the elderly have been more effective than program sponsors for the disabled in securing these limited Section 202 mortgage loans. In 1977 these funds amounted to \$13 million, but in 1978 they mushroomed to \$67 million to create over 2,200 dwelling units. As these funds continue to grow and be available, and as potential sponsors of housing for the disabled become more informed and expert in competing for such funding, the share should increase substantially.

**Housing for the chronically mentally ill** — This group of disabled people in the past has not benefited from HUD's Section 202 Housing Program. Realizing this, HUD initiated a demonstration in 1978 to serve the chronically mentally ill by funding \$15 million in Section 202 direct loan funds and \$2.1 million in Section 8 rent subsidies. In September 1978, these funds were allocated to 58 private nonprofit sponsors in 14 states. Nearly 500 housing units will be made available. A portion of these will be newly constructed, and the remainder will be rehabilitated units. The facilities will be of two types — group homes serving up to twelve persons and residential independent living complexes with up to ten apartment units.

Each facility may provide living accommodations for a resident assistant.

This demonstration has been a model of collaboration between HUD and HEW. HUD is supplying housing, and HEW, through Section 1115 waivers, is making support services available to residents. The success of the venture has prompted the two Departments to repeat the demonstration in 1979 with increased funding.

**Revision of 504 regulations** — In 1978 HUD published proposed regulations outlining the requirements under which various HUD programs would comply with Section 504 of the Rehabilitation Act of 1973, which prevents discrimination against the disabled in any program or activity receiving Federal financial assistance. HUD conducted public hearings in ten regions and received over 500 comments on the regulations. HUD is now analyzing these comments as a prelude to revising the regulations for publication in final form by the end of the summer of 1979. It is anticipated that these regulations perhaps will constitute the most significant contribution that HUD makes this year to the disabled. Once the final regulations are printed in the *Federal Register*, HUD will begin a review to see that the Minimum Property Standards, program handbooks, notices, guidelines, etc. conform to the nondiscrimination rules.

continued on page 73



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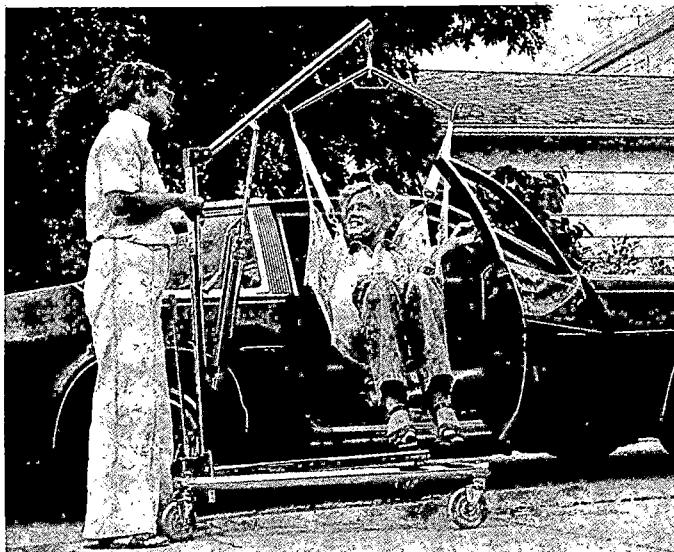
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# **"A critical aspect of any independent living approach is housing, which, if it is to be suitable and satisfying to the disabled, must be influenced by policies and programs at the national level."**

**Independent Living** from page 71

**Technical assistance through HANDI-TAP** — There is a tremendous need for communication and information-sharing among representatives of the housing industry and social services agencies responsible for developing housing options for the disabled. In an effort to meet this need, HUD's Office of Independent Living will be conducting an 18-month technical assistance program beginning in the summer of 1979. HANDI-TAP, as the program is called, will involve 10 regional meetings throughout the country whereby representatives of the housing industry, social service agencies, and disabled consumer groups will gather to discuss the various processes and systems required to develop housing options. Following the regional meetings, six demonstration states will be selected to be funded for a HANDI-TAP Coordinator to be hired for one year to implement various models for housing development in the state.

**Research: ANSI and public housing** — HUD has spent over five years and a half a million dollars to revise the "ANSI (American National Standards Institute) A117.1 1961 (R 1971) Specifications for Making Buildings and Facilities Accessible to and Usable by the Physically Handicapped." The old version, first issued in 1961, has served as the nation's primary source of accessibility design standards. The revision, slated for release this year, will consist largely of mandatory requirements and will provide expanded coverage for kitchens, bathrooms, and other housing elements not considered in the old ANSI A117.1 Standard. It is anticipated that the revision will result in major changes in HUD's Minimum Property Standards, which set design requirements under many HUD programs.

In light of the new Section 504 regulations and the revised ANSI A117.1 Standard, HUD is conducting two studies of its Public Housing Program. The program supports about 1.3 million homes in nearly 10,000 housing projects across the country.

In the first study, HUD is surveying this housing to determine the extent to which it is now accessible to the physically handicapped and the costs of rehabilitating it so as to be accessible in compliance with the new, more strict provisions of the revised ANSI Standard. In the second study, HUD has distributed \$5 million to nine housing authorities so that they can make selected housing projects accessible. Information gained from these two studies will be used in planning alterations to the entire stock of public housing so that it will be substantially accessible.

In other research projects, HUD has examined fabrication and economic feasibility of accessible mobile homes; asked the Batelle Institute at Columbus, Ohio, to investigate issues and policies associated with integrating the disabled into the community; and sponsored a study addressing three issues: How should group homes be designed? Who should live in them? And how should services associated with a group home be developed?

## **A Brief Conclusion**

A critical aspect of any independent living approach is housing, which, if it is to be suitable and satisfying to the

disabled, must be influenced by policies and programs at the national level. At HUD, OILD has been working for the past two years to advance programs that will result in accessible, affordable, community-based housing alternatives for the disabled.

Independent living is an acceptable, cost-effective, and rewarding alternative to long-term, institutional care. The challenge in expansion of the independent living concept in the future is to avoid creating mini-institutions where disabled people are isolated from life experiences. The disabled in America have demonstrated their potential. The goal of independence is changing from a hopeless dream to a living reality. By creatively tapping HUD, other Federal, and state resources, independent living programs are being transformed from theoretical paper exercises. They are now becoming the foundation pillars upon which lives are being given renewed meaning with choice, dignity, and purpose. □

David R. Williamson is the director of the Office of Independent Living for the Disabled at the Department of Housing and Urban Development, Washington, D.C. Statements made in this article do not necessarily reflect the views of the Department.



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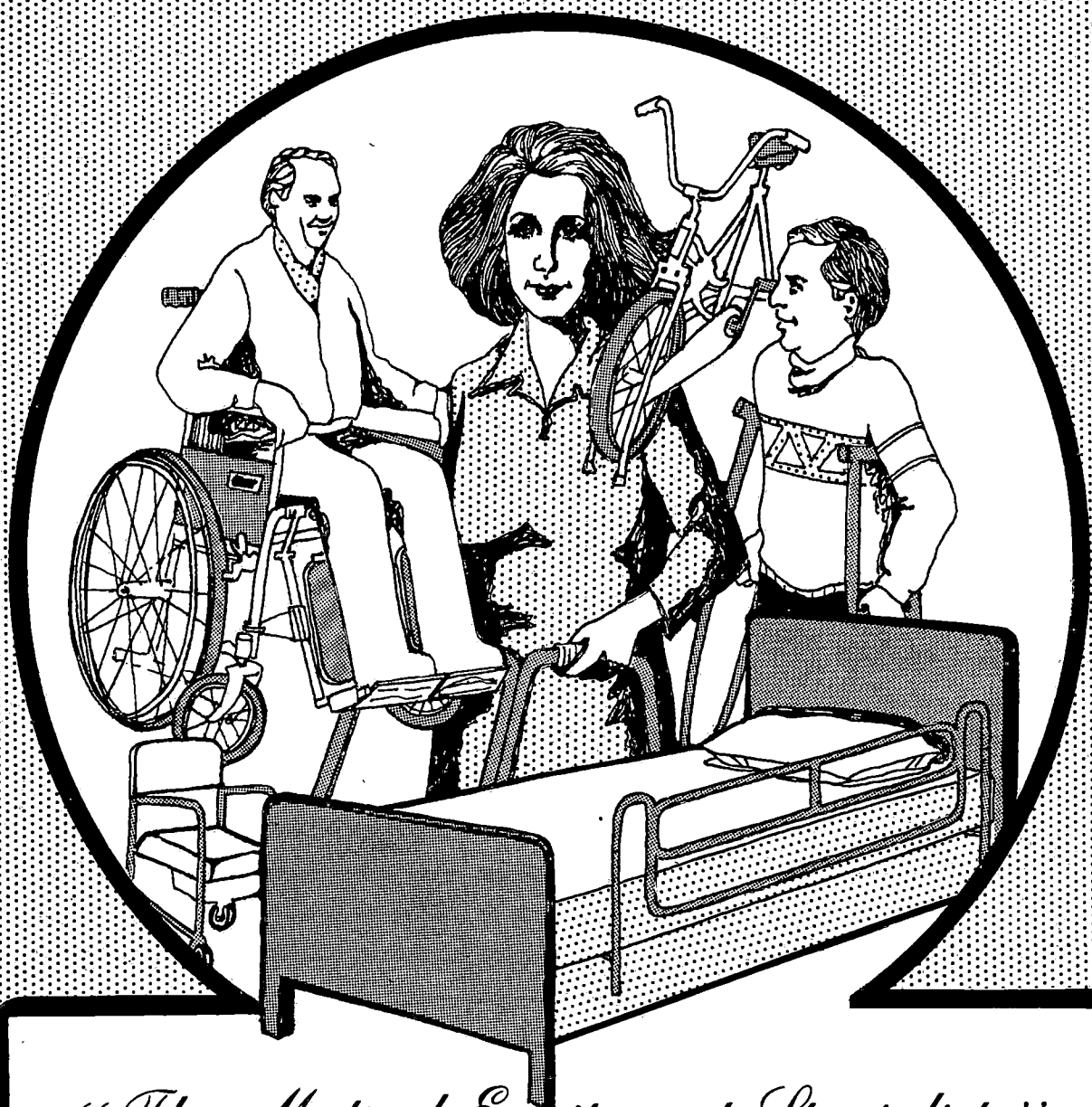
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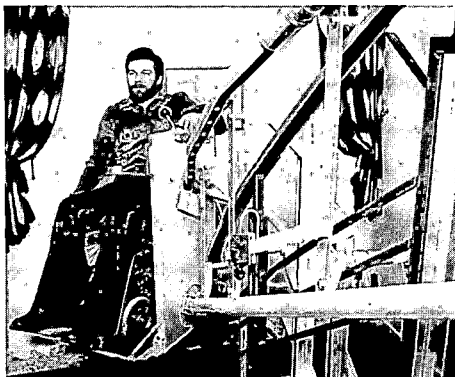
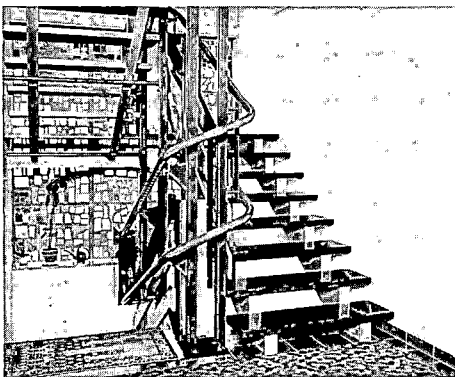
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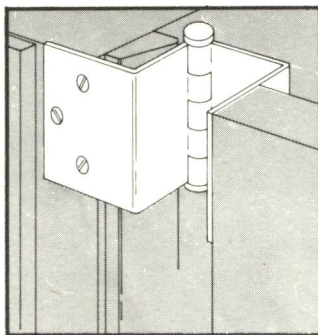
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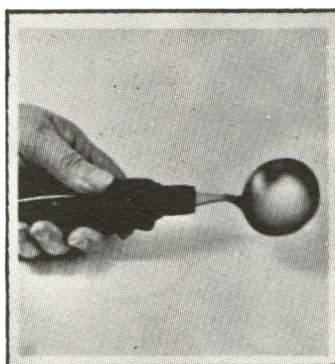
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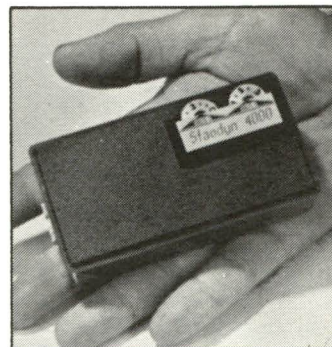
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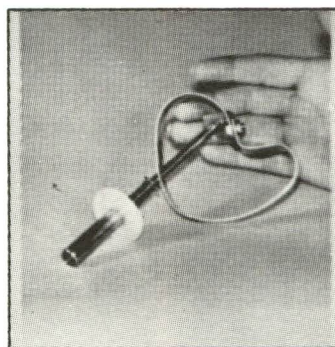
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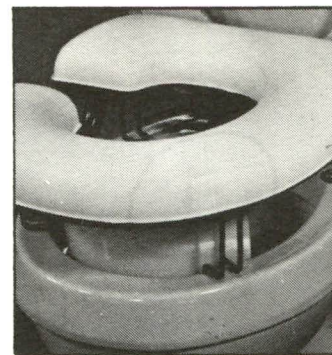
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