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11-26-97 [Health Care, Personnel Policy, Independent Living - 1997-1998]

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Houston TX 77019

Tel 281 987 6666

March 23 1998

Mr. Lex Frieden
Sr. Vice President
The Institute for Rehabilitation and Research
1333 Mousand, In the TX Medical Center
Houston, TX 77030-3405

Dear Lex:

Here are the Rio tickets for you and Max. Thanks for flying out of your way to stay with Continental. I always appreciate your comments from your personal experience with us and look forward to hearing about these flights. Hope your board meeting down south is productive. I look forward to seeing you at the next meeting on April 9th at Bush Intercontinental Airport.

Best Regards,

Jane Cox
Executive Assistant

Enclosure

THE ROBERT WOOD JOHNSON FOUNDATION

MEMORANDUM

To: National Program Staff

From: Frank Karel, Vice President for Communications

Date: February 24, 1998

Subject: American Health Line

I am pleased to tell you that as of today, we will be providing you with free access to American Health Line via NPOnet, the web site created exclusively for use by National Program and Foundation staff.

American Health Line is a daily summary of national health and health care news. We hope that making it available through NPOnet will stimulate more informed exchange on the site about national health issues that might affect your work.

To access Health Line on NPOnet, go to *nponet.rwjf.org,* enter your username and password, and click on the Resources button on the toolbar. Click on "Today's News From American Health Line." You will have access to the current issue, as well as a complete archive of every issue ever produced. Please note that if you have been accessing Health Line through a Foundation-sponsored subscription, your password will expire at the end of February and you will only be able to access Health Line through NPOnet.

If you have any questions about Health Line, please contact Ann Searight in the Communications Office at 609/243-5933. If you have questions about your login and password for NPOnet, please contact the Help Desk in Information Systems at 609/243-5862.

Route 1 and College Road East Post Office Box 2316 Princeton, New Jersey 08543-2316 (609) 452-8701

Internet: http://www.rwjf.org
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Have WW change.
Changes — Send
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Document Originally
Attached to
Following Page

TIRR Systems

PERSONNEL POLICIES AND PROCEDURES

SUBJECT Post-Offer Employment Screening

POLICY NO. TS1.16 **DATE** 7/92

REVISION NO. 2

AUTHORIZATION NO. PPM131

POLICY

As part of TIRR Systems employment procedures, an applicant is required to undergo a post-offer medical examination, including alcohol/drug screenings, that is conducted by a physician designated by TIRR Systems. Any offer of employment that an applicant receives from TIRR Systems or its affiliated facilities is contingent upon, among other things, satisfactory completion of this examination and a determination by the hiring facility and its examining physicians that the applicant is capable of performing the essential functions of the position that has been offered.

As a condition of continued employment, employees may also be required to undergo periodic medical examinations, at times specified by TIRR Systems, which may also include alcohol and drug screenings. In connection with these examinations, employees are required to provide the designated TIRR Systems facility with access to their medical records if requested. Further, it should be understood that the designated TIRR Systems facility receives a full medical report from its examining physicians regarding the applicant's or employee's state of health. TIRR Systems post-offer and drug/alcohol screening medical examinations as well as continued employment exams are paid for in full by the appropriate TIRR Systems facility.

Questions about TIRR Systems-required medical examinations should be directed to your Supervisor, the facility's Personnel Department, or the TIRR Systems office.

PROCEDURE

I. After an applicant has successfully completed the interview process the Personnel Department at the hiring facility will arrange an appointment for a physical exam with a TIRR Systems designated physician.

A. The health examination will consist of at least the following:

1. Medical history

2. Physical examination

3. TB skin test/chest x-ray (TB skin test will not be required for known positives); a chest x-ray will be performed when candidates/employees indicate that they test positive.

a. After a TB test is administered, the applicant will return within forty-eight (48) ho to have the test read.

b. If the result is positive a chest x-ray will be required.

PERSONNEL POLICIES AND PROCEDURES	TITLE: Post-Offer Employment Screening	DATE: 09/02/97	PAGE NO.: 1 of 3	TIRR
	AUTHORIZATION NO.: PP97-107	POLICY NO.: TS1.16	REVISION NO.: 3	

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Memo

To: Kathleen DeSilva

From: Wendy Wilkinson

Subject: Personnel Policy Revision #TS1.16: Post-offer Employment Screening

Date: January 19, 1998

CC: Lex Frieden /Beverly Lawson Adkins

In reviewing the policy referenced above I became concerned about the legality of a portion of it. The portion I am referring to concerns medical examinations of employees, specifically the language, "As a condition of continued employment, employees may also be required to undergo periodic medical examinations...In connection with these examinations, employees are required to provide...access to their medical records."

I am concerned about its legality in light of the prohibitions in the Americans with Disabilities Act (ADA) governing the medical examinations of employees. The Act does allow for employee medical examinations, but only in certain circumstances. Where a medical examination is permissible, it must be strictly limited to eliciting information an employer needs to know for the purposes of providing an accommodation, assessing direct threat or evaluating an employees ability to continue to perform a job. The inquiry must be triggered by a specific event--something which indicates that the employee is having difficulty performing their job. If there is such a trigger, again, the scope of the examination must be strictly limited to eliciting information necessary for providing the accommodation.

Following are the applicable provisions from the regulations and technical assistance manual promulgated by the Equal Employment Opportunity Commission;

"(c) Examination of employees

A covered entity may require a medical examination (and/or inquiry) of an employee that is job-related and consistent with business necessity. A covered entity may make inquiries into the ability of an employee to perform job-related functions.

A covered entity may conduct voluntary medical examinations and activities, including voluntary medical histories, which are part of an employee health program available to employees at the work site."(29 CFR, part 1630.14)

The analysis accompanying the regulations goes on further to clarify:

"The ADA's requirements concerning medical examinations and inquiries of employees are more stringent than those affecting applicants who are being evaluated for employment after a conditional job offer. In order for a medical examination or inquiry to be made of an employee, it must be job related and consistent with business necessity. The need for the examination may be triggered by some evidence of problems related to job performance or safety, or an examination may be necessary to determine whether individuals in physically demanding jobs continue to be fit for duty. In either case, the scope of the examination also must be job-related."

One could argue that the personnel provision referenced is not illegal on its face because, arguably, there are circumstances where a comprehensive medical examination of an employee may be conducted. The key factor will be in assuring that these "triggering" events are understood. This section should be premised with an explanation of legitimate medical inquiries and a description of how extensive they may be. For instance, there could be a scenario where an employee is having difficulty performing his or her job and is subjected to a fairly comprehensive medial examination which includes an evaluation of their medical records in order to determine the appropriate accommodation. To leave this provision in the policy manual as it is, without clarification of and reference to the ADA "triggering" requirements is dangerous and not something I would be comfortable signing off on.

I just wanted to alert you to my concern and let you know that I am available if you have any questions or if I can be of any assistance.

TO: Lex

FROM: Wendy

RE: Commentary on personnel policies and procedures

DATE: March 5, 1993

Following is my commentary on personnel policy number TS1.16;

re: post-offer alcohol/drug screens

These can be conducted but it is important to keep in mind that alcoholics are also protected by the ADA so they should not be screened because of their alcoholism. You can require that employees not drink on the job but can't exclude them from a job because of their alcoholism.

re: Medical examinations of <u>employees</u>

Medical examinations of employees have more stringent requirements. For medical examinations to be conducted of employees they must be "job-related" and consistent with business necessity. An examination would be job-related when the employee is having difficulty performing their job, when an employee becomes disabled, when necessary to determine reasonable accommodation or when <u>required</u> by Federal law or state and local laws which are consistent with the ADA.

The scope of an employee medical examination must also be job related. If an employees job involved lifting and they develop a back impairment they can be seen by an orthopedist but they cannot also be tested for HIV. So it would probably be illegal to request an employees medical records as this would be too broad an inquiry.

Employers may also conduct <u>voluntary</u> medical examinations and inquiries which are part of employee health programs. These programs must be:

1) voluntary;
2) information gathered must not be used to discriminate;
3) information subject to ADA confidentiality requirements.

These records should also be kept confidential subject to the following exceptions:

1) Supervisors where necessary to apprise them of work restrictions and accommodations.

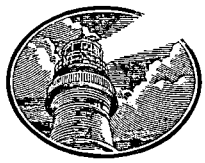
2) First aid and safety personnel where

appropriate if emergency treatment might be required or if specific procedures needed for fire or other evacuations.

3) To government officials investigating compliance with ADA and other laws prohibiting discrimination based on disability.

4) Where required to provide information to state worker's compensation offices in accordance with state law.

5) Where required to provide information to insurance companies providing life or health insurance to employees.



UNUM®

PATRICIA M. OWENS
President
Integrated Disability Management
A Division of Unum America
December 2, 1997

Mr. Lex Frieden
Senior Vice President
Grants/Administration
1333 Moursund Avenue
Houston, Texas 77030

RE: Opportunities Portfolio - Independent Living Initiative

Dear Lex:

It has been some time since we last spoke. I hope all is well and you are enjoying this holiday season. I need to solicit your help/input with regards to a new initiative being undertaken by UNUM. Let me explain.

Opportunities Portfolio
UNUM has undertaken a major project in the ***Opportunities Portfolio - Independent Living Initiative.*** Over the last several months UNUM has designed this Initiative to maximize the social value of our products and extend our disability leadership position. The project originally focused on return-to-work and was a natural progression of our ongoing work to strengthen disability knowledge and risk management competencies.

Opportunities Portfolio is defined as a comprehensive, solutions approach to returning people with disabilities to a more independent and meaningful life (both in and out of work). This effort transcends UNUM technical proficiencies to reach customers on a new, more human level and will provide a clear focus for UNUM on finding ways to help people with disabilities and their families. Matthew K. Gilligan, formerly Vice President and Head of Customer Acquisitions for UNUM's Eastern Region, heads up the Opportunities Portfolio initiative.

Independent Living Initiative (Initiative)
The Independent Living Initiative is one component of the Opportunities Portfolio and concentrates on adding "independent living expertise, service, and funding mechanisms" to our Benefit Management and Product Portfolio. Specifically, the mission of this new UNUM area will be to:

> ***Provide information, referrals, service and guidance to help UNUM customers with disabilities and their families lead more fulfilling and independent lives.***

General Discussion

Information is the foundation from which people with disabilities (and their families) become active in directing their own lives and returning to wellness. Additionally, the social value, implicit in this Initiative is recognizing active and knowledgeable people with disabilities are likely to be gainfully employed.

The Strategy for the Initiative is threefold:

1. For UNUM Customers, we will have an integrated human information point of contact that will be supported by a phone center/web technology.*
   *For the general public web technology will be accessible.
2. Products will be offered to provide funding to help increase people's wellness and independence; to fill gaps in medical insurance programs; and to finance highly qualified "coaches."
3. The staff of Opportunities Portfolio will share disability knowledge and experience with the rest of UNUM, providing all staff with insights to the "human side of disability."

ACTION:

Craig Gray*, Independent Living Initiative, UNUM, will be contacting you during the week of December 8th to discuss this Initiative in more detail. Among the issues Craig would like to discuss with you are:

-Additional details on the Initiative, including:
  -How UNUM will provide support/guidance on the resources available to the disabled; and
  -Products/Riders enabling a claimant to fund services, alterations, etc.
-Your views/comments on this Initiative:
  -How does this sound to you? Can it be improved?
  -Are you aware of any other organization with a similar undertaking?
  -Any potential support/technology connects your organization might be interested in
-Additional "contacts" to help round out the opportunities this Initiative will provide.

*Craig's Portland, ME, number is (207)-770-2943

I greatly appreciate your support and willingness to speak to Craig on UNUM's ***Opportunities Portfolio - Independent Living Initiative.***. Please let me know if I can provide additional information and have a happy, healthy holiday season.

Sincerely,

Patricia M. Owens

cc: Craig Gray

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Warren Professional Building Corporation

Robert J. Mogelnicki
President

November 24, 1997

Mr. Lex Frieden
Institute for Rehabilitation and Research
1333 Moursund
Houston, Texas 77303

Dear Mr. Frieden:

As a proud member of the Henry Kendall College Of Arts & Sciences - Board Of Visitors, I wish to acknowledge your participation in our honorable group. The information presented and distributed in our October 7th meeting shows not only the advancements we have made, but also gives specific direction to the needs of the College. We all feel truly committed and appreciate each gift, whether it be material or through your generous time.

The next scheduled meeting is on Wednesday, March 25, 1998 from 11:00 a.m. until 2:00 p.m.

Have a wonderful holiday season and thank you for your support!

Sincerely,

Bob

RJM/cb

P.O. Box 470372 Tulsa, Oklahoma 74147-0372 (918) 492-8100

German American Chamber of Commerce of the Southern United States, Inc.

FAX

AN/TO:	The Institute for Rehabilitation and Research (TIRR) Attn.: Prof. Lex Frieden Fax 713-799-7095	11/4/97 # OF PAGES: 1
VON/FROM:	Eva Schmoly GACC South, Houston Office Fax 713-877-1602	
Subject		

Dear Professor Frieden,

We were refered to you by Dr. Mikus of Sanmeda Klinikholding KG who told us that you are an expert in the areas of disability and rehabilitation.
As we are in the process of preparing a study on the sector of medical technology in Texas we would like to ask you for your assistance.

We are looking for any information regarding this sector. It would be very helpful to us if you could provide us with a general definition of medical technology, especially which industries are included in this sphere. Furthermore, we are interested in leading manufacturers, associations and research centers engaged in medical technology.

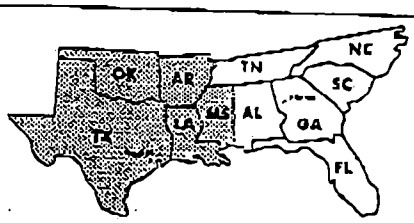
We would appreciate if you could provide us with any information that could be useful to us to carry out this analysis.

Thanking you in advance for your help and cooperation, we remain

Sincerely,

Eva Schmoly
Eva Schmoly
Marketing Associate

Southwest Office
5599 San Felipe, Suite 510
Houston,TX 77056 USA



Tel: (713) 877-1114
Fax: (713) 877-1602
e-mail:gacchou@flex.net

BOLA FASHORO
735 Dulles Avenue, #812
Stafford, Texas 77477
Vph./Fph.: 281/499-5670.

October 26, 1997

Dr. Lex Freiden
Senior Vice-President for Research
The Institute for Rehabilitation Research (TIRR)
1333 Morsund, Houston, Texas 77030-3405

Dear Dr. Freiden :

My family recently relocated to Greater Houston and I am exploring career opportunities in the area.

Sir, your present designation as the Senior Vice-President for Research at TIRR, a highly visible and well-known rehabilitation research hospital in the Texas Medical Center, you have strong and proven skills in research, analysis, design and development of rehabilitative medical devices and systems for the physically disabled.

I beleive you are in a superior position to advice and counsel me in my efforts to advance ny career in the design of innovative, easy-to-control, easy-to-use and cost effective rehabilitation assistive devices. I am making a career transition from teaching and research in engineering academia to applied research in rehabilitation research centers, clinics and hospitals.

Please do not misunderstand me. I am not seeking employment with your organization, nor do I expect you to know of a specific job opening. What I will greatly appreciate is a chance to get your guidance in the pursuit of my objective.

I realize you have a busy schedule and I am only requesting a short meeting. I will call your office soon to establish a convenient time to meet with you.

Sincerely,

Bola Fashoro

BOLA O. FASHORO.

Washington
WASHINGTON·UNIVERSITY·IN·ST·LOUIS
School of Medicine

Program in Occupational Therapy

October 10, 1997

Mr. Lex Frieden
The Institute for Rehabilitation and Research
1333 Moursund Avenue
Houston, TX 77030

Dear Mr. Frieden:

My name is Donna Whitehouse. I am the Coordinator of Student Clinical and Professional Development at Washington University, St. Louis in the Program in Occupational Therapy. Dr. David Gray is on faculty at the Program with me and he suggested that I contact you to discuss ways that perhaps your program and ours could work together.

The Program in Occupational Therapy offers a Masters Level occupational therapy degree. As a part of occupational therapy training, we send students all over the country to learn from other occupational therapists, health professionals and individuals working to promote independence and accessibility for persons with disability. Students must participate in four one-week experiences and a minimum of two three-month internships in order to complete our program.

Dr. Gray felt that your program offered opportunities and services that our students could and should learn about. We are attempting to broaden the scope of occupational therapy, and would like the opportunity to send occupational therapy students to your program to observe, learn and participate in your client interactions.

I would appreciate the opportunity to discuss our program with you further, and explore the possibility of sending students. Please contact me at your earliest convenience: 314/286-1613 or donnaw@ot-link.wust.edu (e-mail address).

Sincerely,

Donna Whitehouse

Donna Whitehouse, MHA, OTR
Coordinator of Student Clinical and
Professional Development

dw/sse

Washington University School of Medicine
at Washington University Medical Center
Campus Box 8505, 4444 Forest Park Ave.
St. Louis, MO 63108-2292
Phone: (314) 286-1600
FAX: (314) 286-1601 Web: http://www.ot.wustl.edu
TDD: (314) 286-1651 e-mail: wuotinfo@ot-link.wustl.edu

TIRR
The Institute for Rehabilitation and Research
1333 Moursund, Houston, Texas 77030-3405
In The Texas Medical Center
Telephone (713) 799-5000, 797-5790 (TDD)
Fax (713) 799-7095

TIRR

October 29, 1997

Ms. Donna Whitehouse, MHA, OTR
Coordinator of Student Clinical and
Professional Development
Washington University School of Medicine
Box 8505 4444 Forest Park Avenue
St. Louis, Missouri 63108-2292

Dear Ms. Whitehouse:

Thank you for your letter regarding collaborating work between the Occupational Therapy program at Washington University and TIRR. I will discuss this matter with my colleagues and be in touch with you shortly.

Sincerely yours,

Lex Frieden
Senior Vice President

Friday, November 7, 1997

Lex:

1) Barrett Markland (512) 454-4816, home: (512) 459-8088 Detailed phonemail message on your machine. Needs to FEDEX this 5-page letter of intent by next Thursday, Nov. 13. they left out the costs associated with administering questionnaire/survey instrument. Of the 36,000 plus people below age 65, how many do they have to survey to make the findings significant?
...something about dual soft hand...

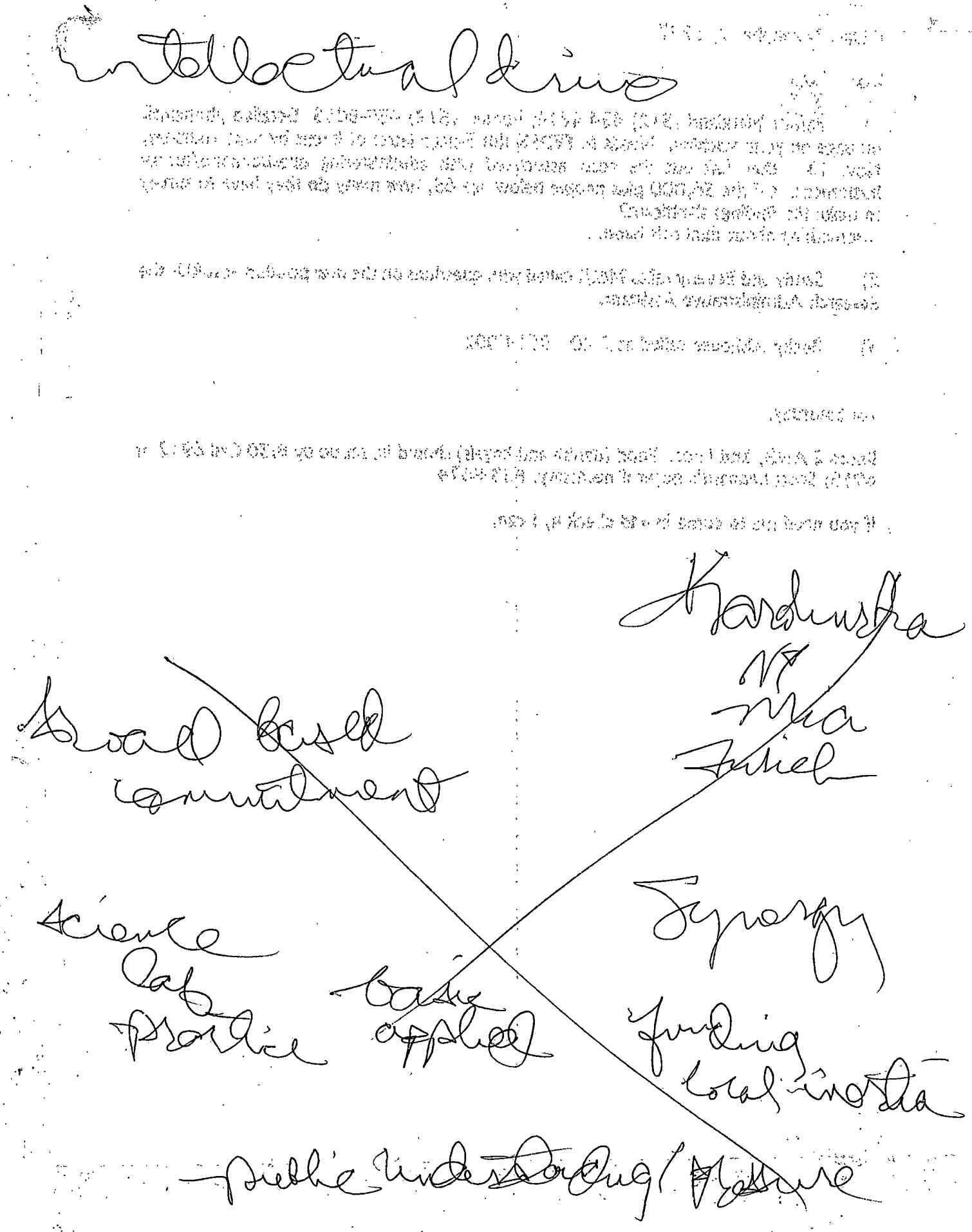
2) Sandy and Beverly (alias Mat]) called with questions on the new position at ILRU--the Research Administrative Assistant.

3) Bucky Alshouse called at 2:40. 951-0002

For Saturday:

Room 2 A&B, 2nd floor. Food (danish and bagels) should be set up by 8:30 Call 6912 or 6918; Scott Leonard's pager if necessary: 833-8674

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№2295

21 AGO 1997

Mr. Lex Frieden,
Senior VicePresident,
The Institute for Rehabilitation Research (TIRR), 1333
Moursund , Houston, Texas 77030, USA
Fax No. 713-799-7095

Dear Mr. Frieden:

Thanks for your fax dated August 4, 1997. We certainly appreciate all the information received from US Council for International Rehabilitation (USCIR).

On May 27, 1997, we also wrote to Dra. Izabel de Loureiro Maior, MD, Vice President for South America for RI exploring the possibility of joining to the South and Latin American Region. The reason is we will not have language barriers. Most of our directors and staff do not have the command of the english. However, on the other hand, travelling to US territory is more frequent and easy from our country.

We are looking forward to an answer from Dra. Loureiro to make our final decission.

In any event, exchange of information from your end will be welcome.

Sincerely yours,

Mary P. Marranzini

Mary P. Marranzini
ADR President

c.c. Miss Susan Parker, RI Secretary General

Institut de réadaptation
en déficience physique
de Québec

MCGILL UNIVERSITY

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Télécopie : (418) 626-3914

Institut universitaire
de réadaptation
et d'intégration sociale

Quebec, September 11th, 1997

Mr. Lex Frieden
Senior Vice President
THE INSTITUTE FOR REHABILITATION AND RESEARCH
1333, Moursund (in the Texas Medical Center)
Houston, Texas
77030-3405

Dear Lex :

Thank you for your letter related to our invitation to organize a possible meeting of *Rehabilitation International* in Quebec City. I really appreciate your support for developing a proposal.

We would be very honoured as a first step to invite the executive board of Rehabilitation International to meet in Quebec City sometime in 1998. Could you carry this formal proposal to the board during your next meeting.

We will be very proud with my team to present to the executive congress board the strength of Quebec City as an excellent site for clinical and scientific reasons in the field of rehabilitation and for linguistic, touristic and facilities potential.

Please, give my best regards to Dr Arthur O'Reilly in Seoul.

I look forward to hearing from you.

Sincerely yours,

Patrick Fougeyrollas, Ph.D.
Scientific Director

PF:jl

MICHIGAN STATE UNIVERSITY

REACH

Rehabilitation Education and CHange
College of Education•Department of Counseling, Educational Psychology
and Special Education•Rehabilitation Counseling Program

215 Erickson Hall
East Lansing, MI 48824-1034
517-432-3623

DATE: May 12, 1997

TO: Lex Frieden
1333 Moursund
Houston, TX 77030

RE: April 28, 1997 Conference

Dear Mr. Frieden,

We would like to Thank You for participating as the guest speaker in "Independent Living For the New MILlennium: Celebrating Our Past and Envisioning Our Future." Your contributions to the event wer very well received by the participants. The day was filled with exciting and encouraging information.

Thanks again. We look forward to working with you in the future.

Sincerely,

Frances Saroki
Rhonda Egidio
REACH

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VOLUME 8 NUMBER 49
OCTOBER 1997

COVERSTORY

THE WOMEN'S ISSUE 38

What do women do when their bodies don't meet societal norms? Some lose self-esteem, but some take the opportunity to redefine womanhood. Some risk intimacy and find love; some lose love and find violence in their own homes. Some challenge their assigned roles in society; some create a manifesto for change. All hope for a culture that, some day, will value women with disabilities. Stories by Nancy Mairs, Jean Dobbs, Laura Kaminker, Miriam Braunstein, Barbara Waxman Fiduccia and Marsha Saxton.

Cover illustration by Melina Fatsiou-Cowan



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28 **THE WORLD SERIES OF POKER** Team NEW MOBILITY aspires to the Big Show and finds its place in the food chain. BY FRED McBEE

21 **MEDICAL MARIJUANA** Does pot help you live with your disability or just get you high? Does it matter? BY YOMI WRONGE

35 **LEAK PROOFING** Incontinence is a cash cow for surgeons, but there's no guarantee of an end to the floods. BY RICHARD HOLICKY



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BULLY PULPIT

Unmixing the Message

Author Naomi Wolf calls it "The Beauty Myth." It's the backlash against feminism that undermines women with narrowly defined beauty ideals that tie appearance to self-worth. It's the punishing cult of physical perfection that keeps women—otherwise advancing in society—from feeling confident and powerful.

Most of us feel oppressed by the myth. Few of us do something as radical as scrapping the whole concept and redefining beauty to include ourselves. But Melina Fatsiou-Cowan has done just that. Melina is the artist who celebrates "Ladies with Scoliosis" in paintings such as the one on this month's cover.

Her work touches me partly because my primary deviation from the norm is scoliosis—24 degrees of separation from a straight spine. The S in my back hardly compares with Melina's, but while I struggle to emulate the expected—a symmetrical torso—Melina boldly creates a feminine aesthetic that embraces her own quirky body.

Melina is ahead of the curve, according to disability scholar Carol Gill, who says women with disabilities are spearheading a movement that all women need to join. "We should see ourselves as pioneers," she says, "as dissidents who will not accept the traditional lines of aesthetics that society draws. There are revolutionaries in every period, and I think *we* are revolutionaries."

Gill envisions myriad sources of cultural revolution, but my particular bent makes me examine the role of magazines.

Many of us, whether or not we subscribe to women's magazines from the dominant culture, feel tyrannized by their content. From advertising, we learn that the beauty continuum is so contracted that, for most of us, it might as well be a single, unattainable point. "So it's Cindy Crawford or bust?" my partner once asked me. On bad days, that's about it.

On good days, we might explore the editorial content of the magazines. From the check-out stand, they shout the secrets of "femininity": how to fix this on you, how to fondle that on him. On good days, it's easy to see the sickness.

But the really twisted message comes from the magazine as a whole. A typical issue offers a gleeful medley of skinny-chic fashion, tips for self-acceptance, cookie-cutter models and admonitions against stereotyping people based on their looks. The ironies, of course, are abundant and ignored: Throughout nearly all women's titles, the mixed message rules. As one friend quips as she flips from article to ad in *Cosmo*: "You're OK, you suck. You're OK, you suck."

A revolution on Gill's scale requires an unmixed message, and that message requires a medium. What magazines do women have that support us without the intermittent put-downs? There aren't many—only *Ms.* and a few low-budget "zines" such as *Fat!So?* and *ABLED!*—that validate women without commercial interruption.

NEW MOBILITY is not a women's magazine—in fact, most of our readers are men—but we still try not to sandwich empowering articles between exploitative ads. We don't always succeed (see this month's letters), but we think of The Beauty Myth as something we are dismantling, not endorsing.

This month, we take on the myth with your stories, strategies and successes. But there is pain, too. Most of you report that the struggle for self-esteem has, at times, been all-consuming, with many setbacks and lasting doubts.

Mainstream magazines have had a hand in this invalidation from without. We hope this one supports a revolution from within. NM

—JEAN DOBBS

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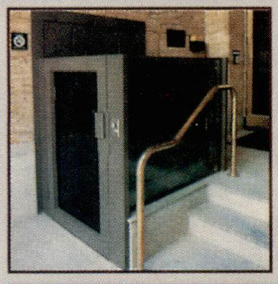
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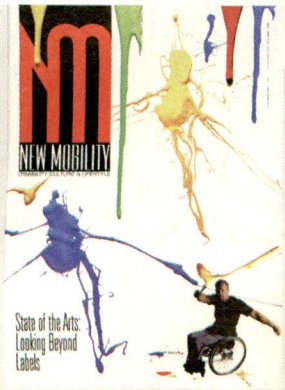
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LETTERS



"Disability art doesn't need to show a person in a wheelchair or depict disability issues as propaganda."

—Richard Treanor

Disability Art

Disability art, if there is such a thing, doesn't need to show a person in a wheelchair or depict disability issues as propaganda. Only the future will tell what contours disability art will take—today, the outlines are indistinct. Yet disabled artists have much to offer disability culture, and we should recognize, stimulate and promote their work, whether or not it reflects disability. Some disabled artists, myself included, want only equal opportunity and, if deserved, recognition of ability.

Richard Treanor
Washington, D.C.

Adding Beauty to Insult

Thanks to Melina for her "Lady with Scoliosis" ["State of the Arts," August 1997]. Scoliosis and its side effects are hard to deal with—she added a touch of hope. Her beautiful words helped my spirit at a time when I am traveling a scary road. She added beauty to insult.

Jo Ann Binkley
Nashville, Tennessee

Lovely and Sensuous

I was so pleased to see Melina Fatsiou-Cowan's lovely and sensuous watercolor, "Lady with Scoliosis," displayed on a full page in the August issue. As a "lady with scoliosis" myself, I used to view my C-shaped body as an ugly deformity. After seeing Melina's work, I have grown to kind of like all my unexpected curves—including my prominent right hip—and think they're sort of interesting in a nonconventional way. Thank you, Melina.

In the same issue, I read Mike Ervin's "Blessed Are the Butt-Wipers" and have concluded that great minds think alike. Life with a disability may have its indignities, but getting your butt wiped is not one of them. In fact, I would think a dirty butt would be much more humiliating. Blessed are the butt-wipers. Amen.

Jo D' Archangelis
Fallbrook, California

Lightning Strikes Once

Wow. You get a great new look for the magazine and then totally blow it with the most offensive ad I've seen in a long time [August 1997]. And on the first page, too! I can't believe that Lightning Handcycles feels it has to resort to this sort of sexist approach. I thought this had gone out of fashion even in gas station calendars. I also thought *NM* had the sense to distinguish the sensual editorial content and ads you have published in the past—which give no offense—from this trash.

Susan Turetzky
Denver

Twice

Tacky, tacky, tacky. Open the August 1997 issue of this magazine, and the ad for Lightning Handcycles hits you (maybe not you, but me as a woman) like a ton of bricks. I am surprised and disappointed that an advertisement so blatantly sexist would be allowed in *any* magazine today.

Alicia Orza
Stillwater, Oklahoma

Thrice

The buxom, partially nude, enhanced woman in the Lightning ad was an affront to disabled women and all other women who do not look like that. For those who already have a poor self-image, this does not make them feel more at home in their bodies.

C.M. Zinser
Owings Mills, Maryland

He Did It the Best

I could certainly relate to Mike Ervin's article "Blessed Are the Butt-Wipers" in the August 1997 issue.

I am a quadriplegic with traumatic brain injury and I have trouble remembering things, especially names. To help compensate, I make up rhymes. On my discharge from the hospital, I wrote a poem in which I mentioned all the hospital's employees by name as well as how they had helped me out. Two lines in that poem gave everybody a laugh:

Then, of course, there's Mike, who let me lay and rest,
Maybe I shouldn't say it, but he wiped my butt the best.

Walter Wilson
Cambridge, Ohio

No Please, No Thank You

A rehab assistant once told me that his primary responsibility was to assist in toileting. He said that for the brief moments it took to help, he considered himself an extension of the young men he aided. He became their hands. No more, no less. No please, no thank you. After all, how could someone, anyone, survive if they had to ask every time that they had to go to the bathroom? How could people maintain their dignity

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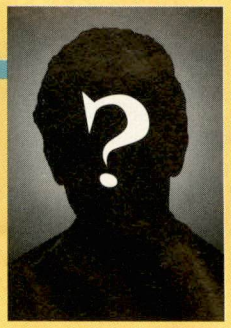
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LETTERS

IN THE LOOP

Person of the Year



In January 1998, NEW MOBILITY will profile its Person of the Year. It might be a national figure or a local hero. Whom would you nominate? Why?

Please submit a brief description of your nominee's accomplishments and, if possible, a way to contact him or her by October 31. Runners-up will be included in a sidebar.

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if they had to give thanks for something so common, so natural, so often?

Deborah Weiss-Grunstein
Santa Fe, New Mexico

New Look

I wanted to comment on the new look. They say you can't judge a book by its cover. I look at yours and think, hmmm, sassy, progressive, clean, trustworthy and accessible: just like the inside. Cool. Keep it up. You're the best.

Dan Wilkins
Luckey, Ohio

Corrections

Pegasus Airwave was inadvertently omitted from September's article on cushions. The company, which makes the Altern8 and other air circulation seating systems, can be reached at 5300 Broken Sound Blvd., Suite 100, Boca Raton, FL 33487; 561/989-9898; 800/443-4325.

The price of the SteeleVest Cooling System was printed incorrectly in the August 1997 issue. The vest with one set of thermal strips is $190. Each additional set of strips is $40.

The correct number for the SCI Hotline is 800/526-3456—not the number published in the 1997-1998 Consumer Guide.

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MY SPIN

The Invisible Woman

By Kiilu Nyasha



I was in tiptop shape before becoming disabled. At age 36 in 1975, I was a student of kung fu, committed to becoming an expert martial artist and setting an example of a disciplined freedom fighter. I imagined myself a black Angela Mao.

However, about six months down the road of strenuous workouts, instead of gaining strength, I began losing it. I was diagnosed with polymyositis, which simply means "many inflamed muscles" and was caused by my autoimmune system attacking my overworked muscles.

Several years and 19 hospitals later, I re-entered society in a motorized wheelchair, a vehicle I had resisted.

About Christmas 1980, I took my first ride along Stockton Street in San Francisco, from North Beach/Chinatown to Downtown. I had no idea how I would be greeted by the general public in my new persona, but I never anticipated the awful reality.

Somehow, I had imagined if there were any changes in how people responded to me as a crip, that it would be with *more* courtesy or kindness. I was shocked by the naked hostility, the contemptuous and condescending stares, the fear of contagion. People literally jumped out of my way, obviously frightened of catching something. Some folks just denied my presence altogether and rendered me invisible.

I soon realized that I couldn't become a shut-in just because other people were ignorant about disability, so I discovered ways to be in public with the minimum emotional stress: I used a Walkman to stay preoccupied with music, news or work (I do radio programming) while rolling through the streets. I kept my eyes focused straight ahead, rarely looking up into the faces of strangers.

As the years passed, I developed a sixth sense about where I needed to use such an avoidance strategy, and where I could be myself and anticipate an occasional nod or smile from passers-by.

Though I was still in my prime with the same face and personality, and a healthy appearance despite my disabilities, I had become invisible to nearly all men. Of course, I felt genuine relief at the lack of sexist aggression—"hey, baby's" and worse—all the disrespect I had suffered throughout my nondisabled youth. But I was devastated by the near total absence of male attention.

I thought I had met a rare exception when a brother asked me out. He was boosting my sagging feminine ego until, on one particular date, he began talking about other women in the same way a guy talks to other men. I responded as gracefully as I could and played out the buddy role, but I began losing confidence in my womanhood.

It took years for me to adjust to my new image and consciously realize that the problem wasn't me—that it was the general public's prejudice, ignorance and superstition. I also became aware of the fact that I had been fighting those same demons as a Black Panther and political activist, except that the prejudices, ignorance and superstition related more to race and class than to physical or mental "wholeness."

Ultimately, my new consciousness gave me the confidence to go to New York and Pittsburgh in 1985, to Los Angeles in '94, Philadelphia in '95, and Belgium and France last February. I'm proud to say that on the last three trips, I traveled alone.

As for men, I've decided my wheelchair is a terrific shit detector. Moreover, it forces me to practice what I've preached to myself and young women for years: Become good friends first with any gentleman you find attractive. Ironically, I've wound up with many really good male friends, but have yet to find my soul mate.

Since the passage of the ADA in 1990, I have noticed gradual improvement in public awareness as more doors literally open to us. As I roll into new social scenes, I have renewed hope for meeting a partner, even though I know now that I can live a fruitful, productive life independently.

Many folks still won't "see" me, but invisibility, I've learned, is in the eye of the beholder. I now believe that at least a few people will see the whole me—as I do. NM

I felt genuine relief at the lack of sexist aggression—"hey, baby's" and worse—but I was devastated by the near total absence of male attention.

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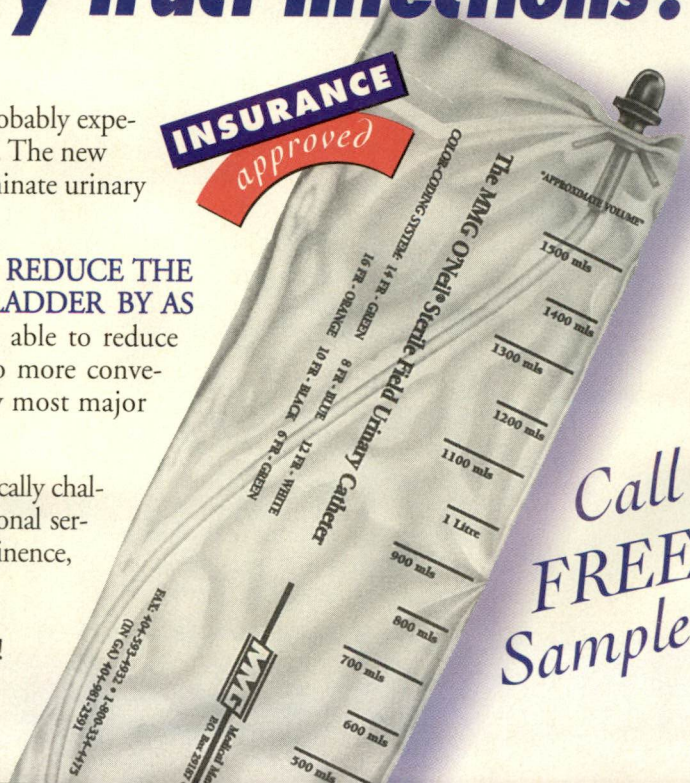
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NEWS



"The disabled are not sick people who never get well; they are citizens who have been denied their rights."

–Evan Kemp

Disability Rights Pioneer Evan Kemp Dies

Disability rights advocate Evan Kemp died August 12 in Washington, D.C. Kemp, who was a former chairman of the U.S. Equal Employment Opportunity Commission and co-founder of Evan Kemp Associates, had been active in seeking equal rights for people with disabilities since his graduation from law school in the 1960s.

Kemp had a rare form of degenerative muscle atrophy called Kugelberg-Weylander syndrome. While working at the Securities Exchange Commission, he sued the government after being denied a promotion because he used a wheelchair. He won his case, and continued to be an active proponent of disability rights.

In 1979, Kemp and a group of investors purchased Invacare Corp., which he encouraged to include people with disabilities in the design and marketing of its products.

In 1987, Kemp was appointed to the EEOC. After a three-year term, he was named chairman of the commission by President Bush. As head of that agency, Kemp helped draft the Americans With Disabilities Act.

In 1993, he founded Evan Kemp Associates, a company whose mission is to provide products and services to enhance the quality of life for people with disabilities.

Kemp was 60 years old when he died. NM

Evan Kemp: 1937-1997

By Hugh Gallagher

Evan Kemp is dead. Ed Roberts is dead. Irv Zola is dead. The founding fathers of the disability rights movement—the ones we counted on to fight for us—are passing from the scene. The Americans With Disabilities Act is their lasting monument.

When I first met Evan 25 years ago, he was director of Ralph Nader's Disability Rights Fund. I was reluctant to meet him. Although I had used a wheelchair since the age of 19, I did not want to see myself as disabled. I certainly did not want to hang out with disabled people.

So when our friend Bob Bernstein introduced us, my first remark, to my eternal shame, was, "I understand you are a professional cripple. I don't like professional cripples."

In spite of this debacle, we soon became friends. For years, we met on Monday nights at a little restaurant called P Street Station. Evan insisted on Monday because that was half-price hamburger night.

Step by step, Evan taught me about disability rights: The disabled are not sick people who never get well; they are citizens who have been denied their rights. He taught me—as he taught us all—that working together we have the power to end discrimination.

I had been right about one thing at our first meeting: Evan Kemp was a professional. I am an old Washington hand, an inside-the-Beltway kind of guy, and I have never seen anyone work this town better. He knew how to pull strings. He knew where the skeletons lay. He always played with the big boys and he always played hardball. Without Evan, ADA would have been impossible. With him, ADA became inevitable.

The last time I saw Evan, a few days before he died, he talked about the need for a new generation of leadership. He felt strongly that there was much more to do. He said that the strength and enthusiasm of new, young leaders was needed now if the movement were to survive.

The best tribute to Evan will be for the movement to go forward under the banner of a youthful, revitalized leadership.

SELF realization



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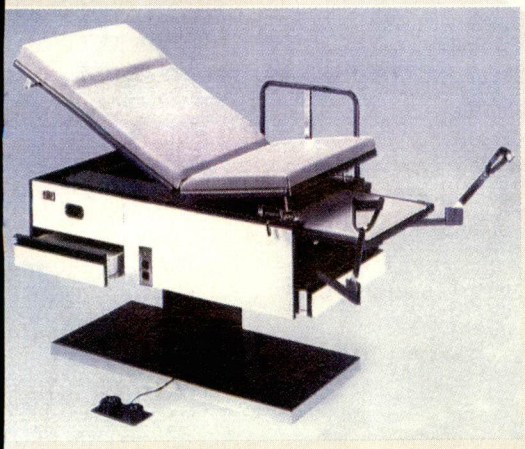
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HEALTH

Women's Health: Sharing Scarce Information

By Sandra Welner, M.D.



A good start to accessible health care is this accessible exam table designed by Dr. Welner.

EDITOR: *For several reasons, women with disabilities often cannot find access to good gynecological care. Their doctors don't believe they could be sexually active, they don't understand disability concerns, or their exam rooms are not accessible. In this article—the first in a series on women's health—Dr. Sandra Welner, an Ob/Gyn specialist with a disability, shares some hard-to-come-by information.*

Vaginal Infections

Vaginal infections such as yeast, Gardnerella and trichomonas are common in all women, but can be more difficult to treat in wheelchair users. Yeast, the most prevalent of the three, grows quickly in dark, moist areas that are not well-ventilated—typical of the vaginal area of wheelchair users. Bladder leakage may contribute more moisture.

Preventive measures include keeping the area clean and dry by using absorbent underclothing—cotton instead of nylon—and a pad that can be changed during the day.

If a yeast infection is diagnosed, it should be treated with intravaginal creams or suppositories. Women who have difficulty inserting medication vaginally may be able to use the equally effective oral Diflucan tablet. (Overuse, however, may result in resistant yeast infections that are very hard to treat.) Nontraditional remedies—available over the counter—include intravaginal caproic acid or boric acid capsules, oral and intravaginal acidophilus capsules, and yogurt with live acidophilus cultures.

It has been long presumed that persistent irritation, redness and tenderness in the vaginal area is just a yeast infection that has not been detected. But sometimes, even multiple anti-yeast treatments are not successful. These cases could represent a condition called vulvar vestibulitis. The cause of this disorder is unclear but is thought to have a neurologic component, and thus has been termed neuropathic pain. Antidepressant medications in doses far lower than those used to treat depression sometimes help alleviate this condition.

UTIs

Urinary tract infections are a common complaint, but prevention depends on the individual situation. If the UTI is caused by bladder muscle dysfunction and inadequate bladder emptying, a simple adjustment in medication may minimize recurrence. Many women, however, find that their bladders require continual vigilance.

Catheterization and sexual activity often introduce bacteria directly into the urethra, and spermicides can decrease resistance to UTIs. Voiding or self-cathing in combination with a one-time dose of an antibiotic such as Macrodantin immediately after sexual activity can help minimize this risk. It has not been proven that cranberry juice prevents recurrence of UTIs, but drinking copious amounts right after intercourse or catheterization has been effective for some women.

UTIs are treated with antibiotics, but when women have had so many infections that they no longer respond to these drugs, surgical reconfiguration of the bladder may be recommended (see "Taming the Lawless Bladder," NEW MOBILITY, October 1996).

Birth Control

Birth control options depend on personal circumstance. A woman with rheumatoid arthritis may improve with oral contraceptives, whereas a woman with lupus may get worse and develop blood clots. Women with paralysis are at increased risk for developing blood clots in their legs when using oral contraceptives that include estrogen. For them, contraceptives containing only progesterone may be safer. These include progesterone-only pills ("mini-pill"), Depo-Provera (a progesterone injection given every three months), and Norplant (progesterone rods implanted under the skin of the upper arm).

All of these methods have side-effects. The mini-pill is slightly less effective than other pills and sometimes causes irregular spotting. Depo-Provera can also cause irregular bleeding, but usually after six months, periods stop altogether due to a significant

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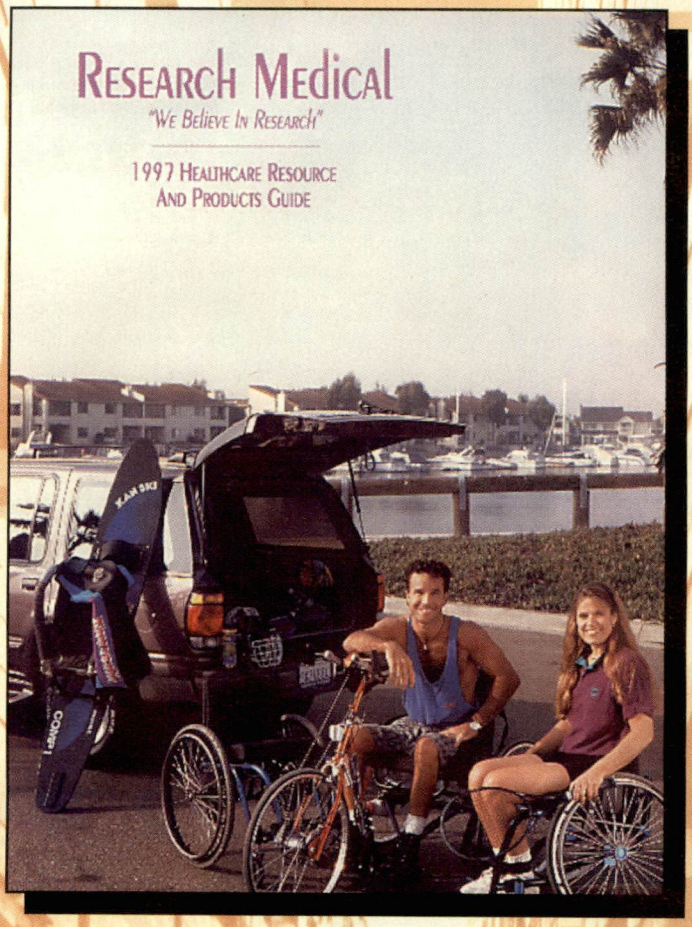
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drop in estrogen levels. Decreased estrogen could lead to thinning of the bones, which may already be a problem for women who are not mobile. Although calcium supplements help prevent osteoporosis when estrogen levels are adequate, they don't work well when estrogen is very low. These concerns should be discussed with a doctor.

Irregular bleeding or cessation of menses is also sometimes seen with Norplant, but estrogen levels remain unaffected, so osteoporosis is a less likely consequence. The major problem with Norplant is difficulty inserting or removing the rods, so women with contractures or spasticity probably should not use this method.

Intrauterine devices provide very effective contraception, but come with a slightly increased risk of pelvic inflammatory disease. IUDs are useful for women with dexterity problems or who can't take the pill because of a history of blood clots, but are less suitable for women with reduced sensation in the pelvic area. Without sensation, a woman may not be able to detect the warning pains of a pelvic infection, and if left untreated, these can be dangerous or, in very rare cases, even fatal.

STDs

Sexually transmitted diseases can occur in any woman who is sexually active or a victim of abuse. Although signs and symptoms may differ according to the woman's physical disability, most untreated infections can enter the bloodstream and cause serious health consequences. STDs fall into two main groups: nonviral infections that can be treated and cured, and viral infections that can be treated to improve symptoms but can never be cured.

Common nonviral STDs include gonorrhea, chlamydia and syphilis. Women with impaired pelvic sensation may experience chlamydia or gonorrhea as increased spasticity or other vague symptoms. There may also be vaginal discharge.

Syphilis is different. At first, it causes only a variable sized ulcer that may not be painful, even to women who have intact sensation. (If you are sexually active and cannot do self-inspections, make sure your attendant alerts you to any skin changes.) This syphilis sore will stick around for three to 12 weeks and will go away by itself without any treatment. The condition, however, is still in the body. The next stage results in flu-like symptoms and skin rash, which may be difficult to identify because some women with chronic disabilities already experience nonspecific aches and pains, and others take medications that cause skin

continued on page 66

WOMEN WITH SCI SOUGHT FOR SEXUAL RESPONSE STUDY

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Marie Dziekan, M.A. Research Assistant, ext. 2711
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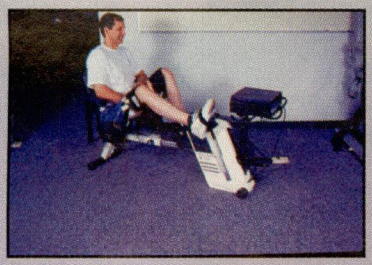


New technology now allows incomplete SCI to use FES walking.





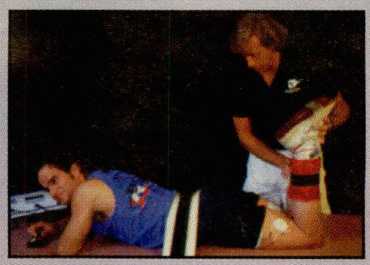
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MEDICAL MARIJUANA:



A miracle medication or an invitation to abuse?

BY YOMI WRONGE

Four years after Barbara Douglas was diagnosed with multiple sclerosis, she heard that smoking pot could ease her pain and was available from the feds. No problem. It did and it was. Each month she visits her doctor's office to pick up 300 primo government-rolled joints.

Her doctor had filed the necessary paperwork at the 11th hour and Douglas, 41, of Lakeside, Iowa, was the last person approved for the Investigative New Drug (IND) compassionate access program before it closed. Today, she is one of eight people the U.S. government provides with cannabis.

Douglas averages 10 cigarettes a day, sometimes more. It depends on the pain. Long, slow drags throughout the day, she says, are like a masseur's hands on her aching back. The throbbing in her legs seems to disappear, and the signature spasms associated with her disease are reduced.

"It's not a cure," Douglas acknowledges. "There is no cure. It makes MS easier to deal with." With it, she spends her days virtually pain-free, cruising around her lakeside community on a Jet Ski with her poodle, Gucci. She exercises regularly in her indoor pool and says a pot-induced appetite has helped put meat on her bones. "My marijuana involvement is very beneficial," she says. "It's not a pill the pharmacist created. It's what God put on the planet."

Douglas has faith in the system. She sits on the board of Patients Out of Time, a group promoting the medical use of marijuana. She has addressed the American Nurses Association about the positive effects of smoking pot, and says she's hopeful that the Food and Drug Administration will legalize marijuana so more people can realize its benefits.

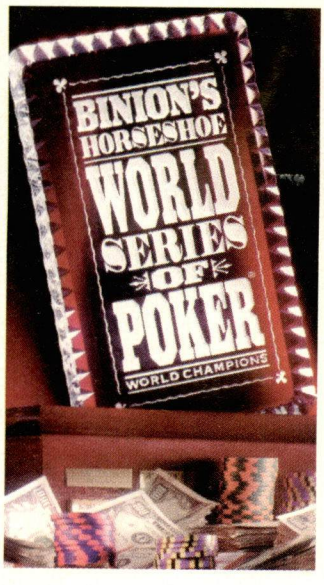
> "It's not a cure. There is no cure. It makes MS easier to deal with."
>
> —Barbara Douglas

"I believe in the government," Douglas says. "I don't

The World Series of Poker:

Team New Mobility Finds Its Place in the Food Chain

BY FRED MCBEE



In *My Little Chickadee*, W.C. Fields sits at a poker table and shuffles the cards. "Is this a game of chance?" his opponent asks. W.C. replies, "Not the way I play it."

There's wisdom in those words. Poker is not a game of chance. It is a game of skill. It is folly to believe otherwise.

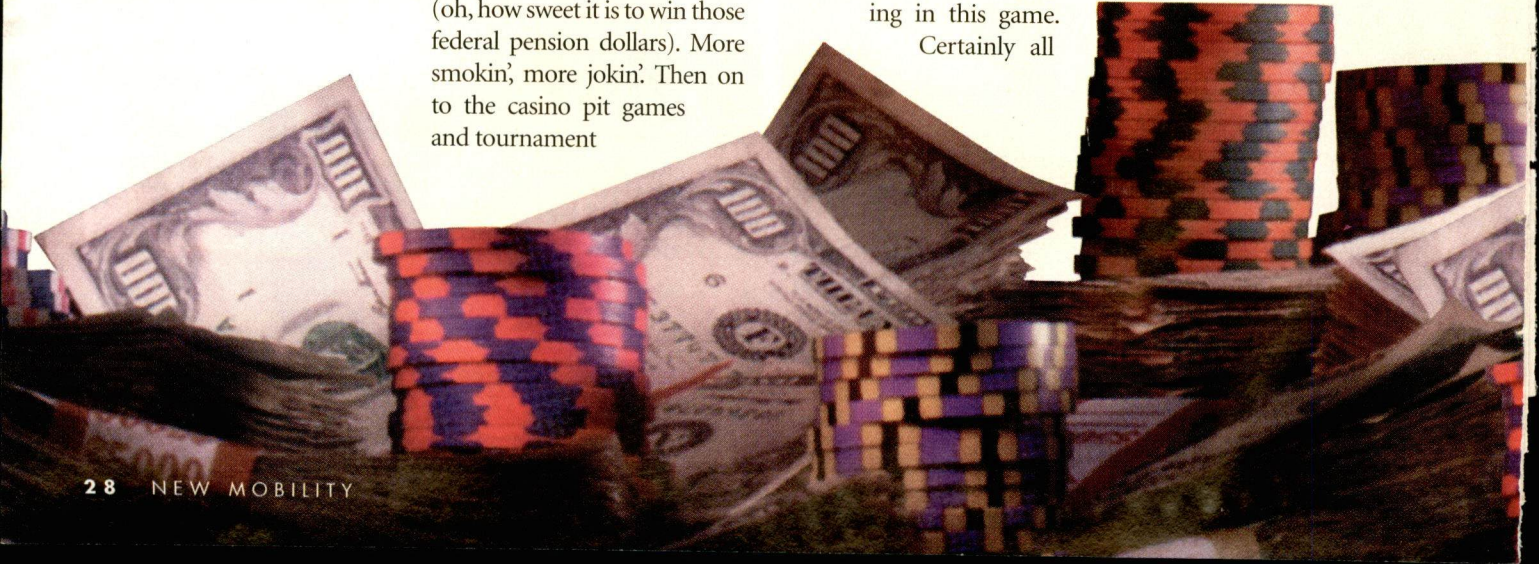
I've been playing poker since my rehab days. Small stakes. Nickel-dime-quarter stuff. Smokin' and jokin'. Then I read a few books and moved into bigger games. Started shoving greenbacks around with service-connected vets (oh, how sweet it is to win those federal pension dollars). More smokin', more jokin'. Then on to the casino pit games and tournament play. Still smokin', no more jokin'. At this level, the water is deep and the fish are big.

My name is on many poker-related mailing lists. That's how I received the brochure from the World Series of Poker. The WSOP is the biggest poker tournament in the world, and it's played every year in Las Vegas at Binion's Horseshoe Casino. More than 300 people ante up $10,000 apiece to sit down at the main event, and the winner goes home with a million plus.

Every poker player in the world fantasizes about playing in this game. Certainly all my card buddies have talked about it for years. We're no different from other poker players—we think we play better than we really do—and when our fancies are flying, we can see ourselves with the big boys at the final table. All it takes is the right cards, right? Wrong. It's important to know your place in the food chain or your wallet will soon become a snot-slick in the deep blue sea.

The Players

I knew I wasn't ready to play with these guys. I was



thinking, "Maybe next year, maybe pigs will fly next year." Then I read about the press tourney:

"As every journalist who covers the WSOP knows, this is a dream assignment: high stakes, drama, colorful characters, great hospitality and food, plus a chance to experience personally—at no charge and possible profit—the thrills and terrors of tournament competition. This special no-limit tournament, with no entry fee or buy-in, is limited to three entrants from each media organization and published freelance writers."

Say what? I've got press credentials. With a little hustle, I could get passes for my researcher and photographer. This was beginning to sound like an idea. I might not be ready to play with the sharks, but I figured I was good enough to rattle chips with other journalists, especially chips I didn't have to pay for. I queried my editor, he faxed Binion's, and, *shazam*, I was in.

I asked Jim Zajac to be my researcher. He's a 'Nam vet and a poker aficionado. He's also a former world-class wheelchair athlete and a legendary outdoorsman. Among his fabled exploits is a moment when, alone in his wheelchair in the dark of dawn on Kodiak Island, he faced off with an 800-pound grizzly at 15 yards. The bear now sits in his den. Had the encounter gone the other way, Zajac would have been a turd on the tundra.

Zajac actually likes to lay his ass on the line. This is the kind of temperament required for a high-stakes no-limit poker player—you've got to like letting it all hang out, and you've got to accept that occasionally you'll get it all chopped off. Most of all, you've got to be nuts about poker—nuts enough to let poker consume you, nuts enough to believe that with monk-like study and practice, you could compete in the big show. This profile fit Zajac like a tailored suit.

I asked Dennis "Boodah Slim" Whidden, an equally legendary figure, to take photos. Boodah's an ex-Marine who killed a whole bunch of people in 'Nam—killed them for you—and he's still mad at you for asking him to do this. After many drug-induced epiphanies, he stopped dancing to any tune but his own. His personal mantra is something like "I ain't playing, and I don't care."

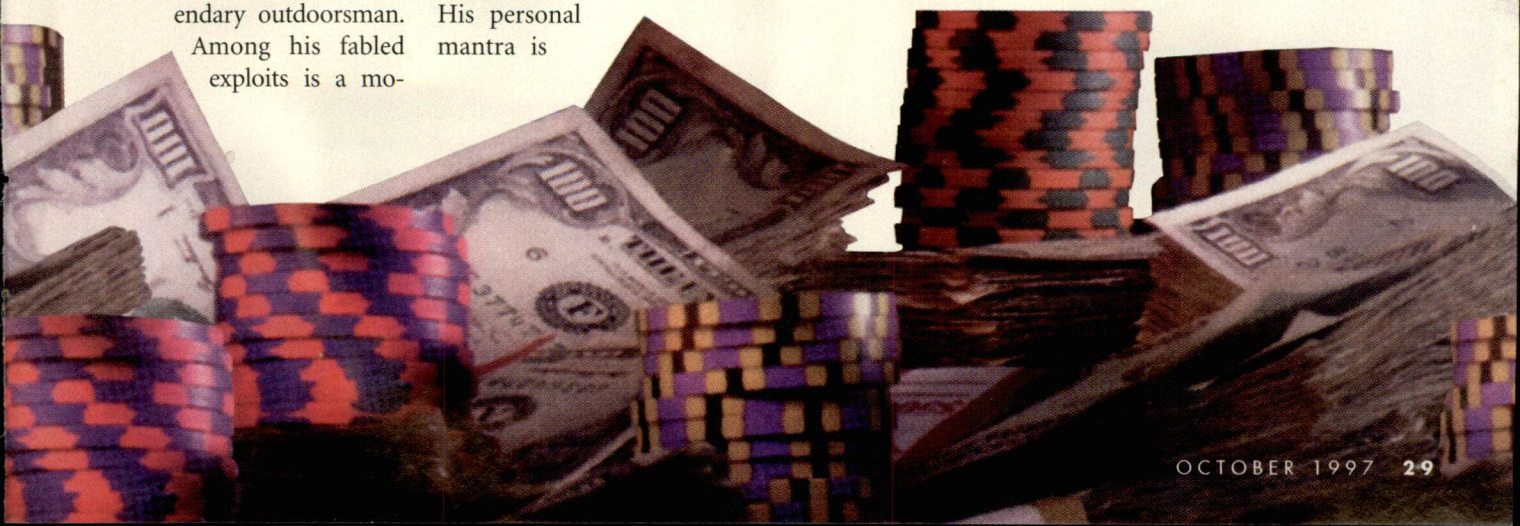
Boodah is celebrated on three continents as a heroic party animal. According to his calculations, he has never done worse than break even in a casino card game. That's because casinos serve free booze. Whenever Boodah Slim sits down, he orders Drambuie by the six-pack and figures he always drinks more than he loses. The casinos love him because he draws a crowd, and it almost never fails that the management offers to employ him as a shill for the house. Boodah plays adequate low-limit poker, but his definition of winning and losing has nothing to do with money. His bottom line is all about karmic merit and cosmic juju.

Yet Boodah was the most sober of our trio, at least when it came to realism about playing in the WSOP. Zajac and I were intoxicated with the prospect that one or both of us could get lucky in a satellite tournament and win our way into the big game. (Hey, it could happen.) This is one delusion the Boodah man did not suffer.

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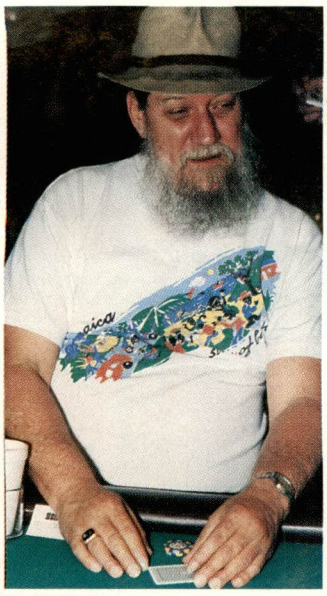
Oasis in Babylon

Disabled vets have a free, accessible place to stay in Las Vegas. Jim Smith and his family operate an 8 1/2 acre condo resort just 20 minutes from the Strip. There are eight condos, each with two bedrooms, air conditioning, covered parking, accessible kitchen and bathroom, and a patio opening onto the pool area. For information, contact the American Wheelchair Veterans Association, 5355 Madre Mesa Drive, Las Vegas, NV 98108; 702/631-1900.



The World Series of Poker

continued from page 29



Photos by Dennis Whidden

Boodah Slim

The Chips Fall

The WSOP lasts four weeks. There are a bunch of satellite tournaments and a couple dozen sub-tourneys that lead up to the final four-day event. You can buy into these tourneys for as little as $100 and if you win, you take a seat in the big game.

We each had our own plan. Zajac went out early to play in the satellite games. He stayed at the Riviera on the Strip, not at Binion's downtown, because a thousand pool shooters were convening at the Riv—superior pool shooters, inferior poker players. Zajac would sit pretty high in this food chain, so he could win his stake into the WSOP satellites by feeding off amateurs. When he went downtown, he'd be playing with the Great Whites. Zajac came to test the waters, but he knew better than to cast his own bread in the ocean.

My plan was less ambitious. I wanted to make a good showing in the press tourney, but I had no expectation that I'd get into the real game. Compared to Zajac, I had not done my homework. I just wanted to see if I could play in this league. I stayed downtown and haunted Binion's.

Boodah followed his everyday plan. He just went with the flow, man. He flowed into town in his new Cadillac. He and his wife, Glenda, a retired Air Force captain and service-connected MSer, stayed at the gimped veterans' resort (see sidebar).

Binion's is the Olympus of Poker, and all the poker gods were in residence for the WSOP. Puggy Pearson, Tom McEvoy, Johnny Chan, Phil Helmuth, Stu Ungar, Huck Seed—we were rubbing shoulders with all the living greats. The casino was comping meals for the players and press, so we'd meet every morning and scarf up the breakfast buffet. Everything except gambling was on the house, just like the old days when the mob ran Vegas and before the Harvard MBAs started squeezing every penny out of a cup of coffee and a local phone call. We miss Guido and Luigi.

Binion's treated us swell. That's why we're going to feel bad when we sue them and every other Vegas casino for violating the ADA. Almost every poker table in the joint was too low to get our chairs under, much lower than the 27-inch clearance required by the feds. Zajac was able to work around this difficulty, but he had to take his feet off the footrests and tie his legs in a knot. I couldn't manage that in my power chair. This was a bummer. It kept me from playing in the satellites, kept me from chasing after my fantasies. "The way I look at it," I said to my lawyer later, "this cost me a million bucks."

Ultimately, the pit boss did some high-stepping and came up with one table we could use for the press tourney. There were 100 entrants—guys from ESPN, major newspapers and magazines, writers of poker books, a large contingent of Brits—and three guys from NEW MOBILITY. I sat near Richard Moll, the big fellow who played "Bull" on *Night Court*. He was there with *Milton*, Milton Berle's new magazine about the good life (its motto: We drink, we smoke, we gamble). Other minor celebrities were introduced before the cards were dealt.

We each started with $1,000 in chips. Boodah played with spiritual abandon and was eliminated shortly after Bull was slaughtered. He was happy to finish in the top 80 percent.



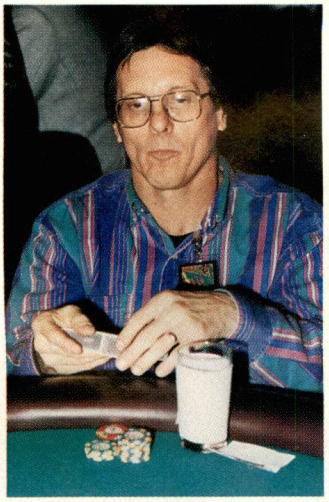
Fred McBee

Zajac and I ended up knocking heads (his hidden aces against my hidden queens), and the sorry dog almost put me out of the tourney. Over the next six hands, I nursed a $25 chip back into a $1,500 stack. In the meantime, Zajac got busted out with a broken flush. I didn't last much longer. I went all in with two pair, only to be last-card-Charlied by an inside straight. Zajac and I finished at the third table, meaning in the

continued on page 32

We're no different from other poker players—we think we play better than we really do—and when our fancies are flying, we can see ourselves with the big boys at the final table.

Jim Zajac





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The World Series of Poker

continued from page 49

top 30 percent. Since I outlasted Zajac and the Boodah man, they must henceforth refer to me as Your Exquisiteness.

Lessons Learned

We met a real poker player the next day. Buddy Williams, a C5 quad, is a professional gambler—one of the top 25 poker players in the world. In his home state of Oklahoma this makes him a criminal, and he's been hauled to the jailhouse a couple times for doing what he does so well. In Nevada and every other place where gaming is legal, he's a star. He had a $10,000 seat at the big game.

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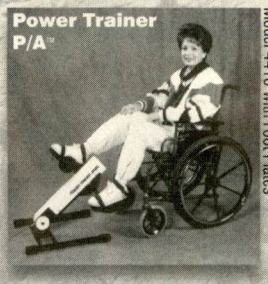
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Buddy's a blood brother. Like me, he was quadded out in Oklahoma in the early '60s, when spinal cord injury care was primitive. We discovered that we'd both spent time in the same rooms of hell at the University Hospital in OKC. Buddy was sent home without rehab to live on his $75 a month Social Security check. He rehabbed himself. Took himself down to the Elks Club poker game and got real good at it, good enough that the Elks invited him to leave. Buddy just got better and better until now he makes his living by wagering tens of thousands of dollars on the turn of a card.

We followed Buddy's progress in the main event. At the end of the first day, his $10,000 stack had dwindled to $4,900. At the end of the second day, he'd built it to $75,000 when he was forced all in on a flush draw. No cigar. He finished 40th in this year's WSOP—out of the money. No problem. He just rolled out to the pit games and refueled his bankroll.

So what did we learn? Zajac learned the most dangerous lesson. He might actually be able to play in this league. He finished in the money at the WSOP satellites, finished high against world-class players, and even knocked off the reigning women's world champion.

Me? I learned that unless I hit the lotto and have $10,000 to throw away, I will never play in the WSOP. The best poker players are like chess masters: Not only are they born with a genius for the game, they are completely dedicated to it. Even if I had the brains for big-time poker, I'm too lazy to work that hard. For the immediate future, I'm sticking to low-limit kitchen table and casino games. If I try to advance beyond that, please wrap me in a cold, wet sheet until I return to my senses.

Boodah waxed philosophical, as always. He said you cannot catch good things by chasing them. You have to let them capture you. After the tourney, he partied hardy at the Riv and money fell from the sky. He shared in a bad beat pot to the tune of $7,700 and hit the slots for several hundred more. The last I saw him, he was waving goodbye from his penthouse suite at the LV Hilton. NM

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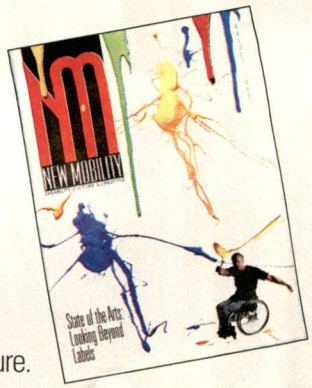
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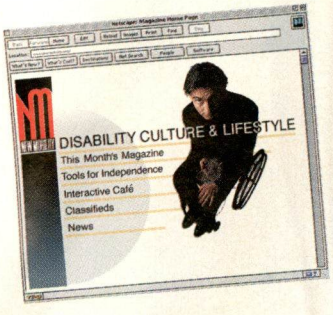
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Leak Proofing

The Joy of Incontinence

BY RICHARD HOLICKY

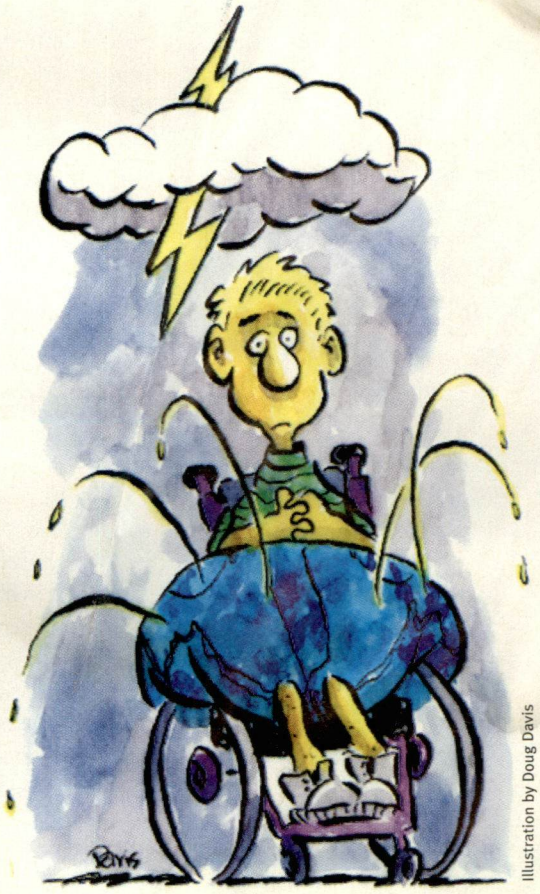


Illustration by Doug Davis

Bladder management following SCI is sort of like a picnic. If it's sunny and dry, it can be enjoyable. Rainy weather is another matter altogether. Plumbing problems can be the thunderstorms that darken your whole day. And these problems—leakage, incontinence, blown catheters, disconnected tubing—are widespread among people with spinal cord injury, and hardly unknown to people with other disabilities.

Anyone who tells you bladder problems and incontinence are no big deal has obviously never been all wet. But for those with adequate hand function to do intermittent catheterization, or at least some sphincter control, there are solutions that don't involve a dose of general anesthesia and several days of hospital food.

While in rehab, I tried an intermittent catheterization program in an effort to see if I would be able to void independently. No dice. A suprapubic tube draining into a legbag seemed like the only logical solution, and the first seven years of my quadrified career were a veritable drought. The occasional rains came only from leaky bags or inadvertent tubing disconnects.

Except for the quarterly urinary tract infections, it wasn't all bad. When summer came, I would simply put a plug in the catheter and wear shorts, as I have enough sensation to feel my bladder becoming uncomfortably full. I also found that a full bladder helped facilitate erectile function. Swimming trunks and bag-free afternoon delight—who could ask for anything more? Then my plumbing broke down, and the floods began.

Initially, the solution of choice was more Ditropan, an anticholinergic drug used to control bladder spasms. This cut accidents down to once or twice a month, although *après la deluge*, the result was still wet clothing, wet corset and occasionally an aroma to die for.

I might be able to cope with the leaking if there were products designed to deal with the aftermath. Unfortunately, no one makes incontinence pads or diapers for use with suprapubic catheters. The best I can do is bend and tape conventional pads over my underwear, and hope they catch the leaking. "Any suggestions?" I asked.

"Let's try a catheter with a bigger balloon," they said. Again, mixed results. Like most who've lived with an indwelling catheter for some time, my bladder is now pretty small, quite muscular, and anything but compliant.

For whatever reason, I leak from the ostomy site, not the urethra. I can't find a physician who will pinpoint the cause, but they all have solutions that will finance a new Lexus or at least a modest ski boat. Their offerings:

- Surgical repair of the ostomy site. Often leakage around the site is caused by formation of scar tissue. Performed in an operating room, a repair usually removes the scar tissue—basically, a roto-rooter job—and sutures the layers of tissue beneath the skin, thus tightening the ostomy hole and limiting the leakage. Expect an overnight in the hospital and about a week or more of tenderness and tightness. No guarantees are given for immediate, much less long-term, success.
- A new ostomy site. "We'll give you a urethral catheter, let the ostomy heal, and then punch a new hole," they s[illegible] "The downside is that [illegible]

or may not work. Plan on being wet for three or four weeks while it's healing." When questioned further, one MD told me that some people *never* heal.

Obviously, neither of the above solutions is a viable option for those who already use urethral caths.

• Bladder augmentation. Outlined by Tami Ridley (see *NM*, October 1996), this procedure is major surgery to enlarge the bladder by using tissue from the bowel. It involves the usual surgical risks, normally a 10-day hospital stay, and lesser complications such as an elevated risk of bladder cancer or the procedure not solving the leakage problem. I've also learned that the augmented bladder may shrink just as fast as the old one did.

• Bladder removal. Even more radical than augmentation, removal requires re-routing the urinary system to an ostomy site and a collection system. A bag is glued to the skin and worn somewhere on the pelvic region, and tubing drains urine to a legbag. No more bare-midriff ensembles or bodybuilding competitions.

• Botox injections. In the confines of an operating room—are you sensing a pattern here?—a strain of botulism is surgically injected into the tissue of the bladder and, in theory, the virus paralyzes the bladder tissue, the spasms cease, and the waters recede. This procedure is used in other areas of the body to compensate for triceps or pectoral spasms, and to relax the frowning muscles of the face to eliminate wrinkles. The urologist who suggested this for my bladder indicated that, *if* successful, the surgery's effect usually lasts from nine to 18 months. Subsequent injections can be done in the doctor's office. Perhaps *E coli* or leeches are next.

An attorney friend was quite impressed with this array of options: "These guys are thinking like lawyers," he said. "Each procedure is designed to generate a steady income. Some of what they do pays for the yacht; the rest simply maintain it."

◆ ◆ ◆

Being less greedy and more creative, I've chosen to market to those who don't opt for any of the surgical solutions. These aren't simply upgraded incontinence pads, mind you, but medically necessary urological products designed with the active crip in mind:

• Clumping Kitty Litter Underwear. All the rage in pet stores, this new generation of litter clumps when wet for easy removal. When it's used in skivvies, it quickly wicks moisture away and can be disposed of at your convenience.

• Gasket Catheter. Building on the bigger balloon theory, this catheter comes with its own self-sealing gasket—interior, exterior or both. The gasket ensures a tight seal and dry, happy campers.

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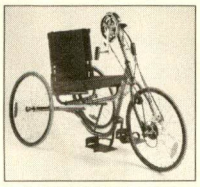
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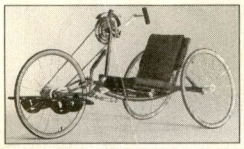
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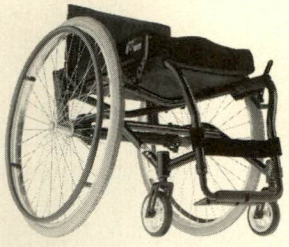
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Women & Disability

The BODY in TROUBLE

BY NANCY MAIRS



Here is my troubled body, dreaming myself into life: a guttering candle in a mound of melted wax, or a bruised pear, ripe beyond palatability, ready for the compost heap. The images, though they vary, always bear the whiff of spoliation. If there ever was a time of unalloyed love, I have long forgotten it, though I had hopes in early adolescence: that my breasts would grow magically larger and my mouth magically smaller; that I would become a strong swimmer and sailor and cyclist; that men, irresistibly drawn, would touch me and I'd burst into flame. Mostly I was, as I was trained to be, disappointed in myself. Even in the '50s, before the dazzle of shopping malls and the soft pornography of advertising for every product from fragrance to bed linen, a girl learned to compare herself unfavorably to an ideal flashed at her on glossy magazine covers and cinema screens, and then to take measures to rectify her all-too-glaring deficiencies. I started painting my lips with Tangee when I was 11, polishing my fingernails as soon as I stopped biting them, and, for my first great love at 13, plucking my eyebrows. At 16, it was green eyeshadow. I strapped on padded bras and squeezed into panty-girdles to ac-centuate the positive and e-liminate the negative. I could not imagine a body that didn't require at least minor structural modification.

I still can't, and neither can any other woman I know. Not long ago, my mother and I shared a mirror as we put on faces for a festive evening. "I hate these," she said, drawing her fingers down the lines from the corners of her mouth, "and this," patting the soft sag of flesh under her chin.

Illustration by Melina Fatsiou-Cowan

I didn't try to protest, though she is a pretty woman, because I hate the same features now developing in my own face. One sister's breasts hang down, she laments, and the other's hips are too broad; my mother-in-law's bosom is too ample; even my daughter, possessed of a body too shapely for complaint, rues her small round nose. All these women, ranging in age from 30 to 84, are active and fit, and fortunately they are too absorbed by their demanding lives to dwell upon whatever defects they perceive themselves to display. None could be considered vain. Not one has mutilated herself with rhinoplasty or liposuction or any of the other measures cosmetic surgeons have developed for emptying women's pockets into their own. Their dissatisfaction with their bodies seems as natural to them as their menses or hot flashes, simply an element of womanly existence.

Even if I hadn't developed MS, then, I'd probably view myself with some distaste. But by the time I was 30, I walked with a limp and used a cane. By 40, I wore a brace on my left leg and used a motorized scooter to cover all but short distances. Now, in my 50s, I divide my time between wheelchair and bed, my belly and feet are swollen from forced inactivity, my shoulders slump, and one of my arms is falling out of its socket.

The other day, when my husband, George, opened a closet door, I glimpsed myself in the mirror recently installed there. "Eek," I squealed, "a cripple!" I was laughing, but as is usually the case, my humor betrayed a deeper, darker reaction. We have almost as many mirrors as a fun house, to give our small quarters an illusion of space, but I avoid looking into them straight on, and I dislike the objective evidence of photos as well. ("If I don't see you," my sister used to tease, her hands over her eyes, "you can't be you!")

I love my wheelchair, a compact electric model called a Quickie P100, and I've spent so much time in it, and become so adept at maneuvering it, that I've literally incorporated it—made it part of my body—and its least ailment sends me into a greater tizzy than my own headaches. But the wheelchair I experience is not "out there" for me to observe, any more than the rest of my body is, and I'm invariably shocked at the sight of myself hunched in its black framework of aluminum and plastic.

Although—or perhaps because—I am appalled by my own appearance, I devote an absurd amount of time and expense to its decoration. "Not for Mom peignoirs and pillows as she takes to her bed," my daughter points out. "No, she still likes to get out and find just the right color turtleneck or the perfect pair of black leggings." The green eyeshadow of youth has proliferated into every color of the rainbow, as well as a number that don't appear there, and been joined by foundation, mascara, blusher and lipstick, not to mention the creams and lotions used to prepare the relentlessly wrinkling surface for this palette. I dread the day when my fingers become so weak that I have to go into the world with my bare face hanging out.

Already I can no longer dress myself, and I quip about moving to a climate so temperate that I wouldn't need any clothing at all; but in truth, of course, I could bear to hang out my bare body even less than my bare face. I buy garment after garment in the hope of finding one to fit


Nancy Mairs

Photo by Sean Justice

I strapped on padded bras and squeezed into panty-girdles to ac-centuate the positive and e-liminate the negative. I could not imagine a body that didn't require at least minor structural modification.

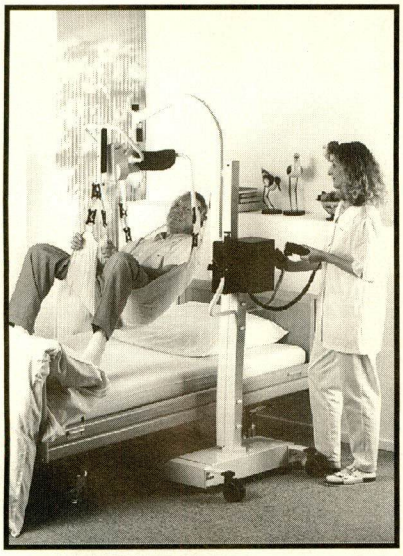
well enough to clothe me in some tatter of grace. Designers conceive tall bony pubescent bodies swinging down runways to some hectic beat on skinny but serviceable legs, and even the apparel that makes it to the outlet stores where I shop is cut for a lithe erect form in motion. This is who I want to be, of course, and so I cruise the aisles searching for a magic cloak that will transform me into her.

The "her" I never was and am not now and never will become. In order to function as the body I am, I must forswear her, seductive though she may be, or make myself mad with self-loathing. In this project, I get virtually no cultural encouragement. Illness and deformity, instead of being thought of as human variants, the consequence of cosmic bad luck, have invariably been portrayed as deviations from the fully human condition, brought on by personal failing or by divine judgment. The afflicted body is never simply that—a creature that suffers, as all creatures suffer from time to time. Rather, it is thought to be "broken," and thus to have lost its original usefulness; or "embattled," and thus in need of militaristic response, its own or someone else's, to whip it back into shape; or "spoiled," and thus a potential menace to the bodies around it. In any case, it is not the sort of thing your average citizen would like to wake up next to tomorrow morning.

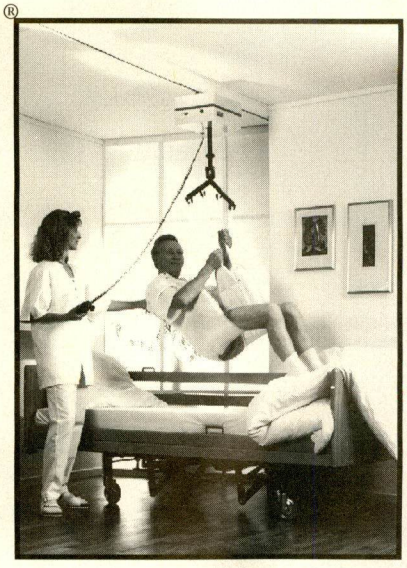
Illness and deformity, instead of being thought of as human variants have invariably been portrayed as deviations.

To embrace such a self requires a sense of permission some people achieve more readily than others. George's body, like mine, has been battered by aging and illness. Liver spots have appeared on the backs of his hands and crow's feet at the corners of his eyes and white hairs in his beard. He bears a puckered scar on his right upper arm. A second scar, in his right armpit, is invisible, but his right breast sags where the muscles were severed. A third runs the length of his abdomen; the surgeon boasted of his handiwork, but frankly George's reconstructed navel looks a little improvised. For several years now he has been impotent, and although I miss his erections sadly, he does not. "I'm at peace with my body," he says. I am at a loss to explain his complacency except as the habit of a lifetime of believing that whatever way he is, is as he ought to be, a confidence that seems to arise in part from the possession of a penis, whether that

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organ itself still rises or does not. He senses himself to be "all right," revising his self-image as necessary to maintain this equilibrium, just as reflexively as I feel myself to be "all wrong."

In fact, he is also at peace with my body in a way that I am not. He always has been, and now that I can do little for myself, he rubs in lotion and sprays on scent, clips nails and stray hairs, wrestles stockings onto my rubbery legs, lifts me off toilets in women's rooms from Los Angeles to London. His ministrations, combining skill with sensuality, reassure me that this is the body he has loved since he first set eyes (or, if recent research is correct, nose) on it 35 years ago. Not long ago, a young clerk in a Victoria's Secret shop, joining in our deliberations over assorted styles and colors of underpants, was clearly startled by George's experienced and critical eye. Settling on a couple of briefs, in a sensible cut but a sexy fabric, he explained that he was the one who had to get me into them, but she still seemed to find his expertise—so patently nonprurient, rather like my grandmother's—a little kinky. Which was, he'd doubtless point out, her problem, not his. The peace he feels with his body has rendered him secure enough in his sexual identity that he enters and exits feminine space with aplomb. George's attentive and affectionate presence provides proof against the revulsion with which I am all too apt to greet myself; and even his easier peace depends in part, I'm sure, on the fact that my body has remained crazy about his body throughout its vicissitudes.

I doubt that any body, whether in trouble or out, can fully conceive a self without an other to stroke it into being and well-being.

I doubt that any body, whether in trouble or out, can fully conceive a self without an other to stroke it—with fingertips and lips, with words and laughter—into being and well-being. Research has demonstrated that infants deprived of touch fail to thrive, and that blood pressure is lowered and spirits are raised in elderly people given pets to caress. If physical stimulation is wholesome—even lifesaving—at the extremes of life, why should we suppose the middle to be any different? Our bodies conceptualize not only themselves but also each other, murmuring: Yes, you are there, Yes, you are you, Yes, you can love and be loved.

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Self-esteem: What Hurts? What Helps?

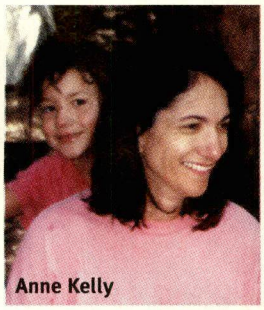
Get Real

Now my self-esteem is very high, but if you had asked these questions a few years ago, the answer would be totally opposite. The media do not present a true image of any woman in society, disabled or not. And the people with disabilities that they present to the public are only the "good-looking" ones—they're never overweight and never, ever have more than one impairment at a time. The thing that helps is remembering who I am and what is really important.

Kathy Hoell, 42
Quadriplegic
Graduate student
Omaha, Nebraska

If Looks Could Kill

When a disability robs you of your body, it robs you of yourself. You are what you see in the mirror and what you feel like when you get up in the morning. If these two perceptions are agonizing, then I would venture to say that self-esteem is no more than self-loathing.


Anne Kelly

Looking at television, with its pretty young things, is just too painful. Magazine articles on weight loss, exercise and health lead to a frustration level bordering on toxic. What would help? If mass media would use more people with disabilities, we'd likely lose some of the freak appeal. If someone would be my friend instead of me being their mission, maybe I'd feel more like a person. Possibly, the mirror would not be so warped, and the pain would be only physical.


Yomi Wronge

Shan Lizotte, 49
Neuromuscular disability
Houston, Texas

Ignore Irrelevance

For some reason, I feel just fine about my body. Mass media has little impact on me, except for the harm I see it doing to my female students. I try to make them aware, as I am, of the manipulation going on there, and of its total irrelevance. What helps? Being busy, happy, having children and good friends, a satisfying job—all those make appearance a lot less important than it might otherwise be.

Anne Kelly, 41, T9 para
High school counselor
Nacogdoches, Texas

No Spoon-feeding

I don't really have issues with self-esteem now, as an adult, but I did as an adolescent. As I got older and became more aware of how the media spoonfeeds images, I was able to take a more critical look. When you get out in the world, you see we don't all look the same. You have to think: My womanness is not all wrapped up in what you see on the outside. Do not judge your value by other people's standards.

Yomi Wronge, 25
Osteogenesis imperfecta
Reporter
Santa Ana, California

In TV Hell

My disability has affected my self-esteem a great deal. Actually, not so much the wheelchair, but the fact that I'm a quad and can't get enough exercise to lose the fat I've gained since my injury. I look in the mirror and I hardly recognize myself.

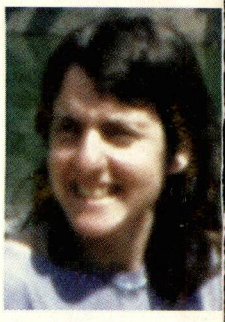

Corie Jones

I know a lot of my low self-esteem comes from society's expectations of what a beautiful woman should look like, and even though I disagree, I can't fight the negative feelings I have about my body. I yearn to look like the thin, muscular women on commercials and TV shows. But this envy did not come from being disabled—I had the same feeling before—but it has gotten stronger since my disability.

Corie Jones, 26
C5 quad, Student
Redding, California

Redefining Womanhood

I have very positive associations about being a woman with a disability, because in 1975, I and other women in Berkeley formed a disabled women's coalition, and we sort of wrote the definition of what it is to be a woman


Susan Sygall

with a disability. I have incorporated the image I try to help other women have. We have to do that: Let women with disabilities be in an environment where we're the majority, to ensure that we haven't internalized negative images.

Susan Sygall, 44
T12/L1 para
Director, Mobility International USA
Eugene, Oregon

Cultural Support

I have no idea what my self-esteem would be without a disability. But there are very few images of women with disabilities, and that's not very good for our self-esteem. Things are changing, and I like seeing a lot of active cultural work by women with disabilities. There are a few positive changes in the media, but our real progress will come from the people in our community itself.



Deborah McCreath

Laura Hershey, 35
Spinal muscular atrophy
Writer
Denver, Colorado

Individuality Intact

It is important to have role models and positive images if we are to find a new sense of self as a person with a disability, and to feel comfortable with our new selves and our presentation to the world. It took me a long time to understand that I could be whatever I chose to be, or look like, and that having a disability does not mean that you give up your individuality.

Chris Kerr, 32, T4 para
Geraldton, Western Australia

Adaptive Thinking

My self-esteem has changed. People react differently. But when the wind changes, all you can do is adjust your sails. Knowing that helped a great deal. I had to adjust how I feel about myself.

Deborah McCreath, 30
C7-8 quad
Ms. Wheelchair Ohio
Cleveland, Ohio

No Scarlet Letter

If anything, my disability has accentuated my innate individuality. Most important, it reminds me to stay in tune with my own inner voice without relying on others, men or women, for validation or approval. Don't worry, be happy—and screw anybody who labels you with that scarlet letter "D" for denial or disability. Use your disability to tune in to your own inner authority and don't be afraid to act on that authority.

Patti Shanaberg, 42
T10 para
President, Global Image Communications
Los Angeles, California



Women & Disability

The Road to Intimacy

BY JEAN DOBBS



Photo by Bibow

Bonnie Jones lost legs and fingers, but still found love.

Before her amputations at age 21, Bonnie Jones flaunted her sexuality. "Afterward," she says, "if somebody knocked on the door—even the UPS guy—I wouldn't answer."

Today, Jones, 40, enjoys a healthy intimate relationship with her partner, Richard Haubner, with whom she shares a home in Southern California. But the journey, she says, was far from short and far from easy. "At first, I was judging myself so harshly that I saw a person who had nothing to offer," she says. "Eventually, I realized that I still had the person I was inside, but I was pushing her down."

Jones' experience reflects that of many women who struggle to build close relationships after a disability. Some obstacles are givens: feelings of loss and shame, awkward new beginnings and, usually, at least one bad match. But the road to intimacy doesn't have to stop there. Hold out, say the women who've gone further, for good sex and true romance.

Picking Up the Pieces

For many women, it's the image in the mirror that deters them from rewarding relationships.

"It was always very hard—and it still is—to believe that someone could love my body the way it is," says Lisa Golem, 36, a C4-5 quad from Verona, N.J.

Golem, injured at 14, says she wouldn't even risk rejection until she was 27, when she went on her first date. During the intervening years, she protected herself from male attention with 120 extra pounds. "Being heavy, I didn't have to deal with the issues of sexuality," she says.

During graduate school, Golem encountered people who were open about sexuality. When she felt ready to let someone get close to her, the extra weight fell off in nine months. "Something inside me had changed, so I felt like presenting myself as open and willing to date. For some reason, that seemed to attract people."

Other women describe similar turning points. Bonnie Julian, 47, L1, was devastated by her first husband's reaction to her injury. "He just couldn't find my body attractive. He couldn't get turned on by me," she says.

Julian, from Littleton, Colo.,

became depressed and was ashamed to be seen in public. "I didn't want to go anywhere. My oldest daughter was 11, and when we'd drive to the store, I'd ask her to go in and get things for me. She was one of my saviors, though. She said, 'No, Mom. We're both going in, or no one's going in.'"

After she started leaving the house more, Julian met her current husband, Art, and realized that a man could still find her attractive. "The first time I was naked in front of him, he said, 'Oh my god, you're gorgeous.' And he had such a look of absolute joy that I actually believed him."

Some women never do come to believe in their attractiveness, and say they depend on lovers to boost their sexual confidence. "I've gotten increasingly discouraged about it because I am older and fatter, and I have scar tissue from numerous surgeries for decubitus ulcers," says Rene, 40, C4-5, from Portland, Ore. "I never really feel good about my body until there's somebody there *making* me feel good about it."

Jones learned the pitfalls of relying on external validation during a doomed marriage. She settled for less, she says, out of fear of rejection. "But when I had my daughter, I wanted to present to her someone with strength of character, so I had to re-evaluate everything: Was it the number of limbs I had that was attractive? I used to think that," she says, "but when I realized I'd lost touch with my spirit through all of this, I wanted it back."

Seeds of Trust

Jones left her marriage and began nurturing her inner self, but it was a long time before she felt secure enough to present her disability openly. "It's really hard as an amputee because I'm one person with my prosthesis on and another with it off. At some point, you have to take your prosthesis off. My walls are down now, but it took years before I could be open and not be afraid."

Her trick? "I try to approach it in a playful way. Then the comfort zone is there and the person says, 'Wow—that wasn't so heavy.'"

Before she learned such finesse, Jones says she freaked out a few people. "I was so serious," she says. She recalls saying one time, rather dramatically, "There's something I really think you should know." Her date looked uncomfortable and leaned closer to her. "I'm wearing two artificial legs," Jones whispered. The man burst out laughing and said, "Wow, I'm really relieved. I already knew that. I thought you were going to say you were a transvestite!"

Learning to take yourself less seriously may help, but women with spinal cord injuries say it's hard to find humor in the prospect of a bowel or bladder accident.

Juli, 34, T2-3, wasn't amused. "I was told in rehab that sex could cause me to lose bowel or bladder control, and that weighed heavily on my mind," she says. But she eventually learned that her lovers weren't as squeamish as she expected, and that her real issue was trust.

"You have to understand that my spinal cord injury wasn't an accident," Juli says. "My ex-husband shot me. When I got out of rehab I didn't want anything to do with men." But when she met one who was open and accepting, Juli was able to bare all. "He really had no expectations, and there was no pressure. I found I had been putting the pressure on myself."

Accidents happen, she says. So does trust.

Shaky Beginnings

If you've learned to believe in your own worth, you may find yourself in the company of highly evolved lovers. But if you're insecure or new at disability, you might find yourself with a creep.

Several women in this story found love through the personal ads, but Jones says you have to be careful what you ask for. Disclosing her amputations, she says, drew the ardor of fetishists.

One man Jones dated for a year was enthusiastic in private, but was ashamed to take the relationship public. "He was a very interesting person, but he just couldn't come out of the closet with [his attraction]." Ultimately, she felt the pain of objectification. "That's my wound," she says. "Now I have somebody in my life who's not about that."

SCI and Orgasm

The secrets of orgasm are many.

Researchers know that it doesn't depend on level of injury or completeness of injury, but they haven't determined which nerve pathways fire the signals of passion. Dr. Marca Sipski is trying to change that. In the last two years, Sipski and her research team at Kessler Institute in New Jersey published two major studies of women with injuries above T6. Here's what they found:

- 52 percent reached orgasm through masturbation. Sex with a partner was not studied.
- Women with complete injuries didn't lubricate from mental stimulation alone; they did with genital touching, but genital stimulation alone didn't translate into a mental turn-on.
- Women with incomplete injuries who could perceive pinprick sensation between their mid-thigh and belly button experienced lubrication from fantasy alone.
- This pinprick sensation was correlated with a higher rate of orgasm, but it was not a requirement.
- The average time to reach orgasm was 35 minutes.
- Descriptions of orgasm were very similar to those of nondisabled participants.
- All orgasms were achieved through genital stimulation. ("Although people have made a big deal out of stimulation above the level of injury, most people will go for below the level of injury," says Sipski.)

continued on page 47

Rene, a lesbian, has had three consensual affairs with attendants, but knows the darker side of personal assistance. When she was 19, she was ill and bedridden with a pressure sore. "I had only one woman taking care of me, and I was so scared of her leaving. So I basically let her sleep with me every night. It was close to rape," she says.

"Now," Rene says, "I'm really careful when an attendant initiates sex. I make sure it's not at a time when I'm feeling sick or vulnerable."

Carol Gill, 48, a polio survivor from Chicago, experienced another brand of bad partner: "the nondisabled man who feels strong and powerful because he's got this woman to take care of. It's not exactly perverted," she says, "but it's not healthy, either."

Good Chemistry

Golem kept her virginity until she was 27, but lost no time after that. "At one point, I was told that I was like a kid in a candy store," she says. "It was very exciting. I was very scared."

But her "adolescence" was short-lived, because she wanted an emotionally healthy relationship. After a few meaningless affairs, she put an ad in the Dallas personals.

"I said I was 6 feet tall with brown hair and a wheelchair. I got about 35 calls and 30 letters. It was a lot of fun. I met a lot of people, a lot of weirdos, and then I met my husband."

She knew she was on the right track when she realized her disability carried no emotional baggage for him. "It never really seemed to make a difference. Sure, it causes problems," Golem says, "but those problems are *physical*, and physical things can be dealt with."

Julian had similar good fortune in her first sexual encounter after her injury. "It was the most wonderful sexual experience of my life," she says. "It was never so free and easy with my ex-husband, even though I was ablebodied then.

"Until that night, I thought that part of my life was over. Afterward, I realized that I was still a woman and attractive and could satisfy a man and be satisfied."

The Big O

So how is it? Really.

"It's different," says Julian. "It's like my body is reacting the same as it used to, but I don't have the surface feelings. It's very intense to me, but it's like warm, wonderful rushing in my entire body. But it's all happening inside, rushing to my brain and without the external feelings."

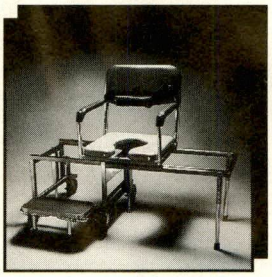
Julian is one of the lucky ones—only half of women with SCI are orgasmic. Researchers still aren't sure what physical factors—if any—contribute (see sidebar), but a few women who experience orgasm offer these observations:

"I don't have any skin sensation—all of my sensation is inside," says Juli. "Sex has to be slow. He has to be at the right angle. I use my fingers to stimulate my clitoris, which also helps. Definitely don't be afraid to touch yourself."

"Lots of foreplay is important," says Golem, who also

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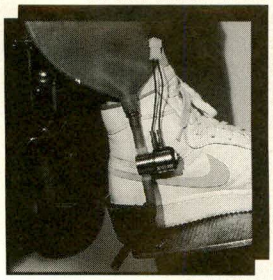


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uses fantasy to reach orgasm. "Whatever makes you feel good is important." She adds that her sex life improved when she switched to a suprapubic catheter. "I used to have it in my urethra, which was not as sexually pleasing," she says.

Teri Michaud Carlson, 38, C5-6, says she gets dysreflexia from direct clitoral stimulation, so deeper pressure works best. "I was the same before my injury," she notes. "I would orgasm only with intercourse, not oral sex."

Rene says physical sensation comes to her primarily through acting out fantasy scenes with sex paraphernalia. "Other lesbians often assume that I want tender, caring sex due to my limitations," she says. "Actually, I prefer something not so tame. Fantasy scenes are especially nice because they require one of my greatest sexual attributes—imagination."

Jody Barker, 25, a T12 para from Los Angeles, says that self-directed concentration helps her achieve orgasm. "You're mentally imagining what you can't feel, so if you can't concentrate, you won't have one. We're always worried about what the man's thinking. We need to be more selfish."

Having it All

Can you have it all—the security, the love, the pleasure of intimacy? "You don't have to settle for anything less," says Golem, who has been married for five years. "There are men out there who can deal with the physical and emotional issues that go with disability."

They're out there, agrees Jones, but you'll never find one unless you believe you deserve it. "It was an accepting of myself to let someone really care for me—to feel like I was worth being cared about," she says.

For Jones, that self-acceptance was hard to win. "You have to develop yourself in other areas of life that make you an interesting person—not just a disabled person," she says. "In the beginning, you're so busy licking your wounds that you can't see that life can still happen for you. I wish someone had told me that, and I wouldn't have wasted so many years worrying so much."

Could she have heard it then?

"That's a really good question. Maybe I heard it when I could." MM

continued from page 45

- Participants were not able to orgasm if their minds were occupied with unrelated mental tasks.
- Blood pressure rose in all the women, but none of the participants with SCI experienced dysreflexia, even when using a vibrator.
- Women who had orgasms were much more likely to be knowledgeable about sexuality and had a higher sex *drive.*

A lot of work remains to be done, says Sipski. Meanwhile, she has this advice: "Masturbate. Most of what people learn about sex comes from masturbation."

Sipski is currently seeking women with injuries at or below T6 for a new study, and is offering participants $500 plus an all-expense paid trip to New Jersey. Call 800/248-3221.

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Women & Disability

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BY LAURA KAMINKER



Photos by Suzanne Levine

"Once he knocked me out of my wheelchair with my baby on my lap. Another time he knocked me out of my chair, through a glass door, then dragged me by my hair through the broken glass." Laura Jackson* speaks quietly and deliberately as she recalls scenes from her marriage. "I remember being kicked around the floor while he was wearing steel-toed army boots. I remember being locked in the bedroom and beaten for three or four days."

Laura Jackson's private hell began in 1967. She was fresh out of high school; her boyfriend had just returned from Vietnam. They left a school dance in his brand-new Camaro, got in an accident, and she became an L1 paraplegic. At that time in the rural Midwest, Jackson says, "there was no such thing as rehab. They taught me a little about transferring, and they sent me home."

But not before inflicting some serious damage. "The physical therapist and the doctor told me there was no point in continuing my relationship, because I could never be a wife. They said a family and children were not in my future." Jackson was frightened. Her boyfriend was guilt-ridden. Six months later, they were married; soon after, Jackson gave birth to their first daughter.

"As soon as I told him I was pregnant, the physical abuse started," Jackson says, attesting to a common pattern. In addition to physical violence, Jackson endured "almost constant" verbal and emotional abuse. But, like anyone who is repeatedly battered, Jackson didn't think of it as abuse, and she blamed herself. "I was always made to feel it was my fault. And that was easy to believe. If I was extremely compliant, he was less likely to hurt me. Therefore, when he did hurt me, it was because I had messed up."

Five years later, the couple's second daughter was born with a life-threatening illness. Under the added stress, Jackson's husband became increasingly violent.

Why did she stay? "I had two small children, one of them drastically ill," Jackson says calmly. "I could not bear the thought of losing custody. In those days, a disabled woman wouldn't have been deemed capable of caring for them." And, she admits, "in the back of my mind, there was that thought: If I leave him, I'm going to end up alone for the rest of my life. He always told me I should be grateful that he took me, since no else would want me.

"During all the years it went on," Jackson says, "it never occurred to me that my disability was a factor in the abuse." Now, Jackson believes her abuser had tremendous guilt over the accident. Raised in an abusive family, he used violence to cope with pain. "He always thought I wasn't walking just to punish him."

They were married 14 years when her husband began threatening her life and her daughters' lives. "I believed him," she says, "and I left." With the help of a neighbor and her Social Security benefits, Jackson rented her own apartment. "He cried continually," she says, "but I was unmoved."

She had no intentions of ever going back. A few months later, the people at Social Security decided that her husband's home was also her asset, and slashed Jackson's benefits by 75 percent. With no other means to support her daughters, Jackson returned to her husband.

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To the uninitiated, Laura Jackson's story might be shocking. But it is all too common.

The statistics are mind-numbing. Every 15 seconds in this country, a woman is beaten. One out of every three American women will be sexually assaulted during her lifetime. If an American woman is murdered, she is five times more likely to be killed by a husband, boyfriend or ex-than by a stranger. Violence against women rages in epidemic proportions in this country, and women with disabilities are no exception.

But until very recently, women with disabilities who were abused were on their own. And although that is still the case in many communities, things are beginning to change.

A central figure in that

Abuse Has Many Faces

"Society has conditioned us to believe that abuse is only hitting," says Maria Palacios of the Houston Area Women's Center. "Women call the hotline and say, he's not really abusive—I mean, he doesn't hit me." But abuse takes several forms, including:

- Emotional: This includes constant criticism, put-downs and threats. Frequent threats—of violence, to sue for child custody or to withhold medication or care—constitute emotional abuse.
- Social: The abuser controls whom the woman is allowed to see, speak to or socialize with. He may not allow her to hold a job or participate in recreational activities. The hallmark of social abuse is extreme jealousy and possessiveness.
- Economic: An abuser will not allow a woman to make her own financial decisions, and prevents her from gaining access to her own money.
- Sexual: Any form of unwanted sexual activity constitutes sexual abuse.
- Physical: This includes slapping, pinching, hair-pulling, pushing or kicking. It also includes the withholding of medication, equipment or personal care.

*This woman's name has been changed to protect her safety.

change is Margaret Nosek, director of the Center for Research on Women with Disabilities. When Nosek founded the center, now part of Baylor College of Medicine in Houston, she wasn't intending to study abuse. But after her research team conducted a detailed nationwide survey of both disabled and nondisabled women, the issue was inescapable. Nosek says, "We concluded that abuse is a central problem for women with disabilities, because we are women."

What you can do

The best way a woman can increase her safety is to increase her awareness. Maria Palacios says, "Abuse is not normal. A lot of women feel that this is their lot in life, and there's nothing they can do about it. But you have rights! This is against the law."

If you're in an abusive relationship, or think you might be, seek support. "Always let other people know what's going on," says Palacios. "This can be very difficult, because isolation is one of the tools of the abuser. But do your utmost to tell someone—a trusted friend, your family, a counselor. And always do know that somehow, somewhere, you're going to find support."

While some professionals believe that the incidence of abuse is much higher among disabled women, Nosek's researchers didn't find evidence to support this. They were, however, able to define the ways in which disability can change the experience of abuse. For example, very few battered women's shelters are accessible, and most hotline counselors aren't versed in disability issues. Disability may cause a greater economic and physical dependence on the abuser, making it more difficult to escape. Disability may create other avenues for abuse, such as withholding medication or orthotic equipment, or refusal to do personal care.

Legal hurdles are daunting for any battered woman—it's difficult to advocate for yourself when your self-esteem has been destroyed. Abusers often threaten women with a custody battle. For a woman with a disability, this threat may be all too real. Nosek says, "We've seen so many cases where abusers are granted custody, using the argument that her disability makes her an unfit mother." Counselors tell stories of women with cerebral palsy calling the police, only to be written off as drunks. Nosek, a wheelchair user herself, says, "In these situations, all the attitudinal and physical barriers come into play."

What Nosek's team uncovered was a dire need for networking and education. "There's

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one industry set up to deal with disability," Nosek explains. "Then there's another network helping women who are battered. But they're not linked in any way."

In eight years of graduate work in rehab counseling, Nosek never encountered a single lesson on the signs of domestic violence. "We were never introduced to the symptoms of battered women," she recalls. "This would be extremely relevant to a woman's rehab process, but it's not in the curriculum."

On the other side of the equation, Nosek found a late start and good intentions. "The battered women's network has only recently become aware of the necessity of serving women with disabilities. They want to learn about ADA, but they're so poorly funded that it's very difficult for them to come into compliance." In addition to the financial obstacles, Nosek says, the women's network "doesn't know how they should modify their hotlines or what their counselors should know."

To those ends, the Center for Research on Women with Disabilities is bringing the two systems together, and cross-training them. "We're educating disability service providers, increasing their awareness of abuse, so they can identify women who are abused and refer them to appropriate services," says Nosek. But she cautions that a unilateral approach is ineffective. "Let's say you have a counselor who suddenly realizes that 10 percent of her clients are being abused, and she refers them all to the local women's center. What's the center going to do? The shelters are filled to capacity, they're turning women away. So getting more resources to women's centers is a very serious problem.

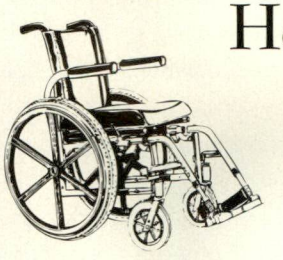
"Somehow we have to create a tide that's going to raise all the boats."

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The Houston Area Women's Center, one of a handful of disability-friendly women's centers in the country, floats on that tide. Maria Palacios, the center's hotline case manager, describes HAWC as "one of the few places that serves women and also has a keen awareness of disability, as opposed to an ILC with an increased awareness of abuse. We see all women as women first." In addition to its fully accessible shelter, HAWC has incorporated a disability-sensitivity component into all its program training, and educates local disability service providers about domestic violence and sexual assault.

Palacios, who uses a wheelchair as a result of childhood polio, trains and supervises the hotline volunteers, and stands at the ready to handle more challenging crisis calls herself. She says, "If a client

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has a disability, we go that extra mile to find out what her specific needs are. There may be transportation issues; finding housing for her may be more challenging. Another major challenge may be attendant care. Perhaps we can help her arrange for an attendant at the shelter. Or perhaps her attendant is the abuser. Then the woman has to face the fear of confronting a system that may deny her the services she needs to survive. We will support her and advocate for her."

If a woman is physically dependent on her abuser, the "safety plan" strategies that counselors often work out with clients may not be appropriate. As Nosek says, "Everything on the list—hide money, hide keys, have a friend you can signal if you're in danger—takes on different dimensions when you have a disability. You can't ask your perpetrator, 'Can you put this money inside this tampon box?'" The disability-aware crisis counselor understands these obstacles. "Serving women with disabilities," Palacios emphasizes, "means much more than putting a ramp in a shelter."

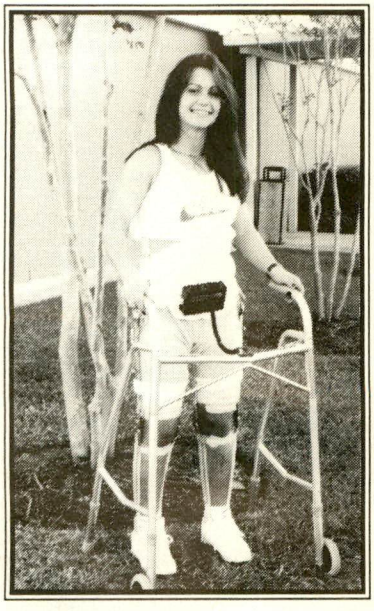
Palacios also points out another way that disability may create the opportunity for abuse. "In our society, people with disabilities have been conditioned to be compliant and submissive. The average woman with a disability may be more prone to think of herself as 'less than' than the average woman without a disability. If she is in an abusive relationship, she may be more likely to think, 'This is the best I can do, who else would have me?'" But Palacios cautions against generalizations. "All women in our society are vulnerable to abuse."

continued on page 54

Old Myths Die Hard

These are some of the most commonly held myths about spouse, partner or caregiver violence:

- "I brought it on myself. If I change my behavior, he'll treat me nicer." Abuse is never your own fault. Every person is responsible for his or her own behavior. The abuser—not the victim—is responsible for abusive behavior. No one ever deserves to be mistreated.
- "I can change him." You didn't make him abusive, and you can't make him not abusive.
- "It was a one-time-only incident. It will never happen again." If he hit you once, take it seriously. Make it clear to him that you deserve to be treated better, and you will not tolerate that behavior. If you disregard the first instance of violence, you can be almost certain it will happen again.



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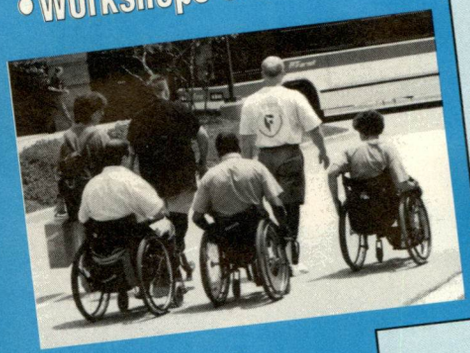
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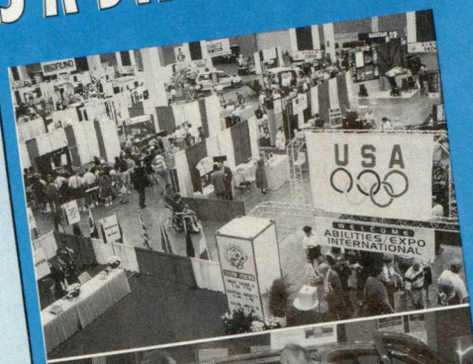
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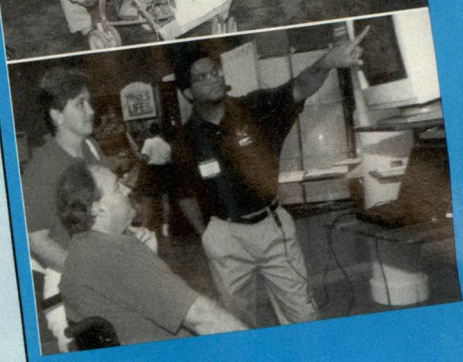
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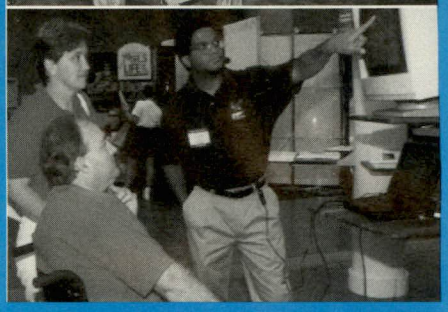
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continued from page 52

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Laura Jackson had no disability-friendly women's center to call. She had very little money, and virtually no self-esteem. But two years ago, Jackson left her husband. She got a lawyer, an order of protection and a divorce. When local authorities wouldn't enforce the court order, she moved to a different city. With the support of her adult daughters and the help of a trusted employer, she started a new life.

"I left my children and my grandchild behind. I came to a place where I didn't know anyone and, in my mid-40s, started over with zero—no furniture, no kitchen items, nothing." It has been a very difficult journey—financially, physically and emotionally. But she wouldn't change a thing.

"I was dying there," says Jackson. "I had no volition. Every conversation I had, every decision I made, was based on what his reaction would be." To those who fear that leaving is more dangerous than staying, Jackson says, "it's true that more women are killed when they leave. But staying didn't guarantee me safety. At least if you leave, there's a chance.

"There are all kinds of survival. There's physical survival, but there's emotional survival, there's your sanity. There's the quality of your existence. I would not go back, no matter what the risk."

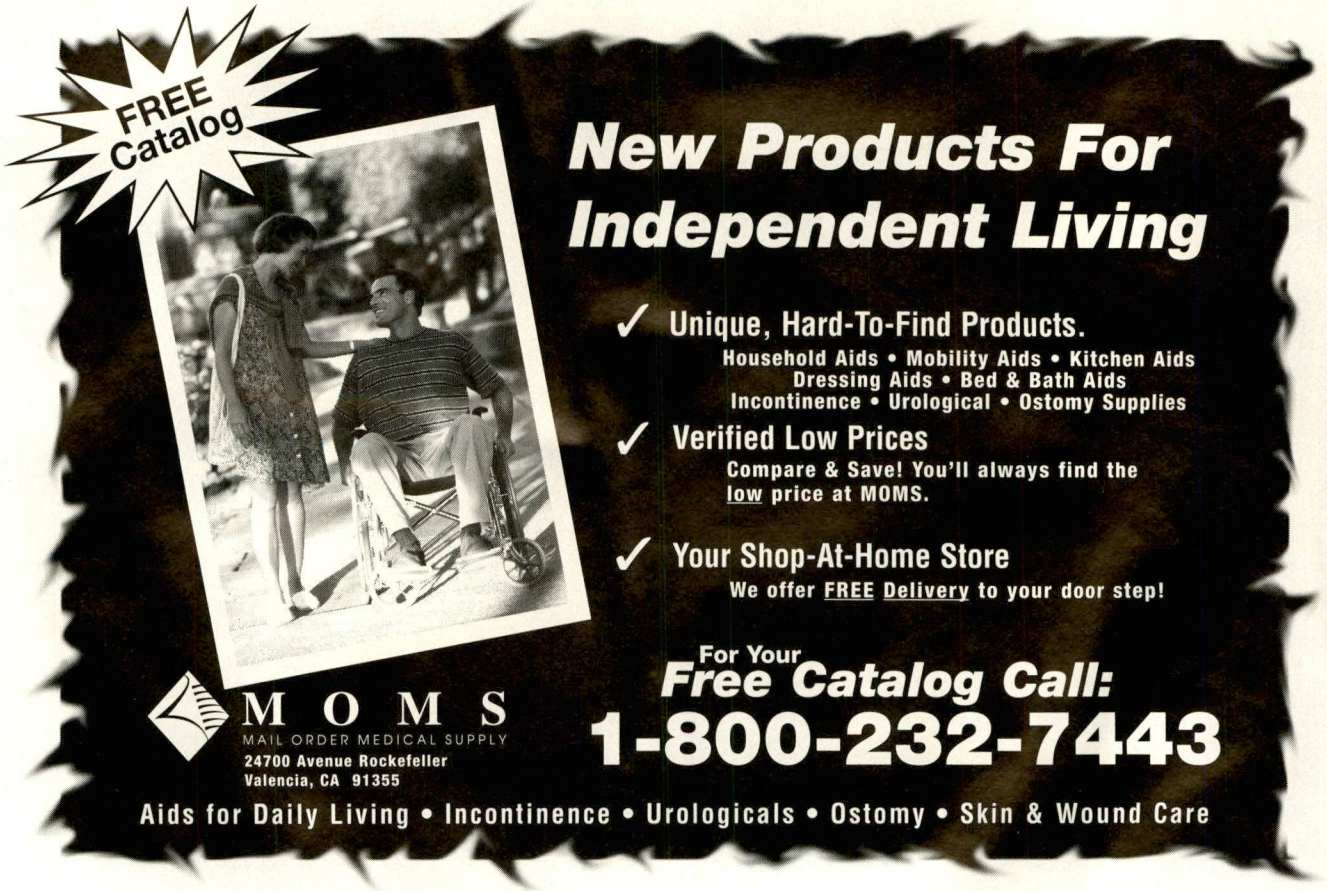
Now Jackson's quiet voice becomes urgent. "This is the most important thing," she insists. "Even with the added problems caused by a disability, and the poverty that goes with it, it can still be done. I want women to know that it's not impossible. I need women to know that you can get out, and you can survive. It may not be cushy, it may not be pretty, but, by god, you'll be doing it, and you'll get your life back."

What does Laura Jackson look forward to in the future?

"Peace." NM

Resources

- National Domestic Violence Hotline, 800/799-7233
- National Resource Center on Domestic Violence, 800/537-2238
- National Coalition Against Domestic Violence, 303/839-1852
- RAINN-Rape, Abuse and Incest National Network, 800/656-HOPE
- Look in your local Yellow Pages under "Domestic Violence," "Battered Women," Sexual Assault Services" or "Victim's Services."
- For a copy of *ESCAPE! A Handbook for Battered Women Who Have Disabilities,* call or write Finex House, P.O. Box 1154, Jamaica Plain, MA 02130; 617/288-1054.



Change of View

By O.M. Baker

Even though I had seen my alcoholic father terrorize and beat my mother, I was not afraid of him. My daddy loved me. I sensed that a major factor in my powers of enchantment over my violent father were the physical disabilities visited upon me by a case of polio when I was a toddler. I was "special," and this specialness was my magic shield.

Throughout my childhood and teen years, I held on to this unspoken belief that I was somehow protected from harm by a universal rule of fair play: No one hits a gimp.

Then one morning, 16 years ago, this childish belief exploded in a white-hot bomb of pain. I couldn't believe what was happening, even as I felt the bone-jarring blow come crashing into my left eye and watched in horror as his fist rose again. My husband of seven years and the father of my two children was beating me. The shattering of my faith was almost as traumatic as the pain and fear.

Beaten and terrorized as I had seen my mother years before, I survived that day and I got out. Yet nothing has looked the same to me since. The sight in my eye was permanently damaged and, likewise, my view of humanity. I saw that my specialness didn't motivate my neighbors to respond to my screams or prompt the police to treat me with dignity. All illusions smashed, I saw that being disabled does not protect me from violence, domestic or otherwise. I saw that love and commitment will not rein in the monster of uncontrolled rage, even in the man who professes love and commitment. This last eye opener was perhaps the most painful of all.



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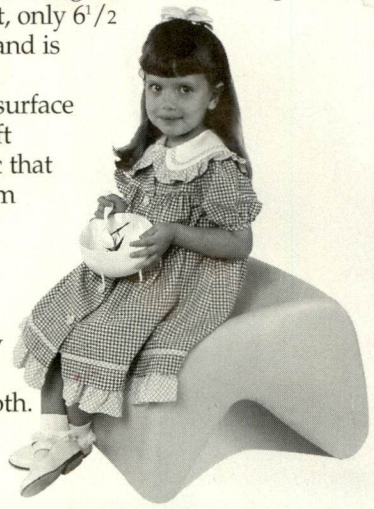
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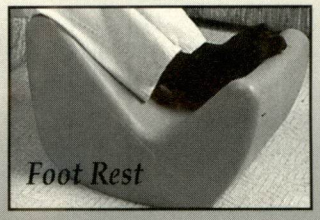
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Beyond Stereotypes

BY MIRIAM BRAUNSTEIN

In all aspects of life, women with disabilities—perhaps more than others—face confining labels and attempts to place limitations on what they can and can't do. The women whose stories follow have met stereotyping head on, and found solutions that build acceptance and opportunity.



Ing Wong

ING WONG: A Quick Study

Ing Wong is nothing if not quick. The 24-year-old admits freely to having a "dazzling sardonic wit," and also readily states that Canadian Broadcasting Corporation Television, where she works as a journalist and researcher, is "similar to CNN, but it's Canadian and much better quality."

Considering the journalism job market in Toronto, Wong says she's grateful to be working at all—but even more grateful in light of the combination of her gender and disability. Discrimination isn't blatant, she says, but it exists.

"In Canada, we're a country known for our subtleties," Wong says. "I have sometimes sensed that people have doubted my ability to get the job done. I'm a woman, I'm in a wheelchair, I'm Asian, and I'm young, so it's a quadruple whammy."

Most discrimination she notices is because she's disabled, Wong says, and comes from both men and women. But her gender does set her up for some problems that men with disabilities don't face.

"Men with disabilities have a hell of a lot more credibility," she says. "And I notice especially that older white male friends who are disabled seem to be 'in' a little bit more than I am. It's a little bit more of a struggle to be taken seriously."

But Wong doesn't concern herself too much with other people's skepticism. She simply proves them wrong. "I'm as quick as or quicker than anyone in the newsroom," she says.

For the most part, Wong's problems are outside the workplace. In Canada, no law like the ADA has been instituted, she says, and accessibility is a problem. There is little public transit, for instance, and she often prefers to cruise the distance from home to work in her wheelchair. But her criticisms of her country don't go too far; she is a staunch defender of all things Canadian—especially the health insurance program, which insures all citizens, and a benefits program that provides attendant care even for working people.

For now, the barriers that do exist don't bother Wong. She has enough ambition to pursue her career, spend time with her family and buy vast amounts of makeup, which she admits is her only hobby (though she is constantly encouraged to basket weave). And ambition is what you need to get by, she says.

"Get your ambitions in line," she says. "Get a good education, and don't depend on anybody financially. Women do have to work harder, we do have to be better. But in the end, I think we'll still come out on top."

SASCHA BITTNER: Young, Disabled and Wry

It sums up Sascha Bittner's personality that she really wanted to attend her high school senior trip and "just have fun." It sums up her spirit that when the high school denied her that right, she took it to court. And won.

Bittner, 23, a senior at the University of California-Berkeley, has been combining a powerful desire to participate with a need to fight for her rights all her life. She is quadriplegic, with perceptual problems and a severe speech impediment, because of cerebral palsy. And while finding acceptance in school and society has been a struggle, it hasn't been without its high points.

Her list of activities reads like a primer for civic awareness. In addition to doing extensive volunteer work, mostly with AIDS patients, she belongs to several disability rights groups, including ADAPT and the Keys to Introducing Disability in Society (KIDS) program. She also performs with the Wry Crips Theater Group and was a finalist in *Sassy* magazine's "Sassiest Girl in America" contest.

Wry Crips has been one of her favorites, though. She first joined the group at 15, under the guidance of founder Cheryl Marie Wade.

"I had taken drama in high school, but there was never a part for me to play," she says. "In Wry Crips, I had a voice interpreter and could finally express myself artistically. It was very liberating, plus I am a total ham, so all in all, a wonderful experience."


Sascha Bittner

Photo by Suzanne Levine

But Wry Crips has taken a back seat recently to the KIDS program. As one of the program coordinators, Bittner makes speeches to kids from preschool to high school age, touching on subjects ranging from disability culture to personal assistance services to in-school teasing.

"A lot of it is just dispelling their stereotypes of what my life must be like," Bittner says. "They learn that I'm just a normal young woman who happens to have a disability."

The KIDS program also provides credit for the other big drain on her time these days—finishing her social welfare degree. After she's done with that, she says, she'd like an M.S.W., and then a job working with youth with disabilities. That sort of work is important, she says, judging from her own experience as a teen with a disability. While she had a lot more support than some, girls at that age need all the help they can get.

"I was lucky," she says. "Actually, I could have used even more support, but most teen girls with disabilities get nothing at this very difficult time of their lives."

And that lack of support, Bittner says, is what leads women with disabilities to accept the inequalities society gives them. If she had her way, all of her peers would be "young, disabled and proud."

SYLVIA LEE: Doing What She Loves

Sylvia Lee resents the assumption that being a full-time mother and wife isn't work. In fact, she says, that kind of thinking is what holds us back. Instead, women need to be able to choose from the widest variety of occupations—including homemaker.

"We are all individuals," says Lee, 36. "We need to follow our hearts. Whatever we feel we should do is what we should do—not what society thinks we should do. I love being a mother and a wife, and disabled or 'abled,' it's what I would do."


Photo by Susan Parker

Sylvia Lee

Lee's family—daughters Jessica, 18, Amelia, 15, and Shawna, 12, and husband, Tim—come first in her life. After that, she mentions her work as a model of everything from wheelchairs to clothing. She began getting

jobs five years ago, after attending a modeling school. So far, she has had good luck finding work, as well as good luck with her marriage and children. In fact, the only bad luck was the bus accident that made her, at age 17, a T11-12 paraplegic.

But Lee mentions the accident casually and deals with it casually. It was difficult, of course, but both she and her then-fledgling marriage survived, and both are stronger for the experience. And her ambitions came through intact as well.

"I always wanted a family," Lee says. "When I got hurt, I didn't let that stop me. I knew that I'd be able to have children." Her first daughter came along sooner after the accident than she'd have liked, she says, but it worked out well.

"It was like medicine for me," she says. "I've always loved children very much. It really gave me something to live for."

Since then, her career as mother has been fulfilling, if not easy. Adaptations had to be made, she says, but her husband helped and her daughters deal with her disability well. And with Mom using a wheelchair, perhaps the girls are better equipped with self-esteem than most young women.

"If anything," Lee says, "it has strengthened them."



Sandy Welner

SANDY WELNER: Pushing the Wheels of Progress

Sandy Welner can't remember exactly when she decided to become a doctor, but she does know that she has always wanted to take care of people. Gynecology, her specialty, required more thought.

"It was an evolving process," says Welner, 38. "When I went to medical school, I was going to be a plastic surgeon, because I did so much with my hands." After her obstetrics/gynecology rotation, however, Welner decided that she preferred the human aspects of medicine to surgical practice.

Her adjustment to disability has evolved as well, since an accident at age 28, when she had been in practice for two years.

After two years of rehabilitation and a lot of support from her family and physiatrist, Welner made a great deal of progress, though she still has balance and coordination problems. "I do almost everything I want without too many limitations," she says. "I'm just really slow. My new life is a slow-moving life."

After rehab, Welner returned to work, which was one thing—along with her mind—that still moved quickly. And the field of women's health is so vast, she says, that it has become more and more fascinating to her. "There's not just one thing—there are so many things, because women are so diverse."

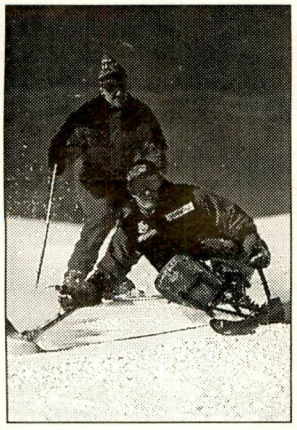
Women with disabilities are just as diverse, she believes. Unfortunately, Welner says, many medical professionals carry misconceptions about them—such as that they're more vulnerable and less capable than nondisabled women—and these assumptions can lead to inadequate care and a lack of support. She tries to use her own experience as a woman with a disability to change that experience for her own patients.

"I had a woman with a stroke who was crying. She was crying that she couldn't do the things she did anymore," Welner says. "I said to her 'I understand. But it will get better. It'll take time.' And she said to me, 'I know you know what you're talking about. You're not just giving me this bull.' There's a certain way of relating to somebody that they can tell when you say 'I understand,' that you really do."

She hopes her work will help physicians see that the medical and psychosocial needs of women with disabilities are often overlooked. "It is getting better," she says. "The wheels of progress turn

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slowly. And I think it's encouraging that people are starting to ask questions. Doctors are starting to call me up and ask, 'What do we do about this stuff—we never thought about it.' Well, it's great that they're thinking about it. Because that's the first step."

LINDA NOBLE TOPF: Building Self-Empowerment

Linda Noble Topf has changed a lot since her multiple sclerosis diagnosis 19 years ago. Then the 29-year-old president of her own design company, she was an energetic "type-A" personality—a graphic designer, painter and copywriter.

At 47 and a full-time electric scooter user, Noble Topf says MS has taken that energy from her. But although she is older and her disability has progressed, she is also wiser, more peaceful and more accepting.

Noble Topf's journey to self-acceptance is the basis of her recent book, *You Are Not Your Illness: Seven Principles for Meeting the Challenge,* which she began writing in 1988 after she retired as a designer. Along with her own experience, the book chronicles the information she collected through the MS Initiative, the group she founded in her native Philadelphia and eventually took national.

The book, she says, is about self-compassion, self-acceptance and self-love—three things she had trouble with after her diagnosis.

"After winning awards across the planet and now not being able to hold a pen," Noble Topf says, "I thought, 'Well, who am I now? And how can I use this as an opportunity, rather than something to collapse into?'"

Her first obstacle was simply accepting her illness and the limitations it caused. "I had to ask myself, 'Am I worthy to help?' I [wanted] to do everything myself," she says. "The way I lived my life, for me to ask for assistance meant that I'm not good enough or weak."

After self-acceptance, she says, came forgiveness and eventually self-love. This process and these principles offer self-empowerment, she says, and are applicable to all women.

"Whether they are ill, or they're aging, or they're injured, or their husband picks up and leaves after 25 years, or they go financially bankrupt, or any other adversity that life has to offer—this is information women need to hear."


Linda Noble Topf

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Women & Disability

Disability Feminism: A Manifesto

BY BARBARA WAXMAN FIDUCCIA AND MARSHA SAXTON



Barbara Waxman Fiduccia signs her marriage contract. The big day came after years of haggling with the Social Security Administration for a waiver that keeps her ventilator and attendant services from being casualties of wedlock.

Disabled women live at the crossroads of disability and womanhood. Our feminist awareness—and even our consciousness of ourselves as women—is affected by living with two minority identities and two sets of barriers to achieving our life goals.

In challenging our double discrimination, we are drawing strength and strategy from both the disability and women's rights movements, but this new feminism—disability feminism—is distinct in some ways.

Ours is a broader movement because narrow definitions of feminism exclude disabled women. We may need assistance in daily living, which has led some nondisabled women to imply that we cannot be *real* feminists because we don't have the requisite financial or physical independence. These notions hurt and limit all women, but they especially alienate disabled women.

We have other unique concerns. Mainstream feminists have battled limited gender roles for nondisabled women: sex object, wife and mother. But as disabled women, we've had the opposite problem: We've been denied sexual, spousal or maternal roles when we wanted them. However, the spirit of feminism—the empowerment of women—remains the key goal of our movement. Here are some areas in which we seek empowerment:

Sexuality

Women with disabilities have been sexually and socially segregated, and discouraged from expressing our sexuality.

We have a difficult time finding accurate information about sexuality or body image. Our questions about orgasm, fertility, sexual positions, childbirth, breast size and weight gain are often evaded or disregarded. This is devastating to women who must work against social stigma to feel good about their bodies and believe they are entitled to sexual pleasure.

In her article "Cultivating Common Ground," psychologist and disability feminist Carol Gill describes our situation: "Keeping us genderless by discounting us as women and as sexual beings helps to prevent us from reproducing, which keeps us harmless to society. And, once we are categorized as non-breeders, we are discarded as socially useless and join post-menopausal women in health care limbo."

- **We want our sexuality accepted and supported with accurate information.**

Reproductive Health Care

Disabled women are still not treated like "real" women with "real women's bodies." Many of us are still not offered birth control, while others are forced to use birth control or even sterilized against their will. Inaccessible exam tables and mammography machines mean we are routinely passed over for cervical or breast cancer screening and treatment.

- **We want equal access to reproductive health care.**

Marriage and Family

For many disabled women, getting married is a radical act. Most SSI or Medicaid beneficiaries who marry partners who are not on SSI or Medicaid lose their eligibility for health and personal assistance benefits. Many must choose to keep their benefits to avoid grave health risks. But if we don't marry, we lose an opportunity for a social and emotional support system that would enhance our ability to live and contribute in the mainstream of society. The marriage penalty also complicates the decision to conceive for those whose religion or beliefs proscribe raising children outside of marriage.

• We want legislators to eliminate disincentives to the marriage of people with disabilities.

Motherhood

Many disabled women are told they can't become mothers because they would be incompetent parents or would pass on their disability. Disability feminists want to ensure that disabled women can have and raise children. We want to develop more resources for mothers with disabilities to care for their own children and to have access to adoption.

• We want disabled mothers to be treated with respect.

Abortion

Women with disabilities have reported significant difficulties in relation to abortion, including pressure to undergo an abortion, because it is assumed that a disabled woman cannot be a good parent; or denial of abortion, because a guardian decides she is incapable of making her own reproductive choices.

• We want uncoerced choice.

Prenatal testing and selective abortion

Many women are pressured to use prenatal tests to find out if their unborn baby has a genetic condition. Then they are encouraged or forced to have an abortion to avoid babies that would become disabled people—a high-tech form of ableism—instead of loving children for whoever they are and simply because they are born.

• We want all women to understand that they can refuse to have these tests if they don't want them. We want children with disabilities to feel welcome in the world.

Barbara Waxman Fiduccia, an expert in the reproductive rights of women with disabilities, is ADA Project Director for the California Family Health Council in Cupertino, Calif.

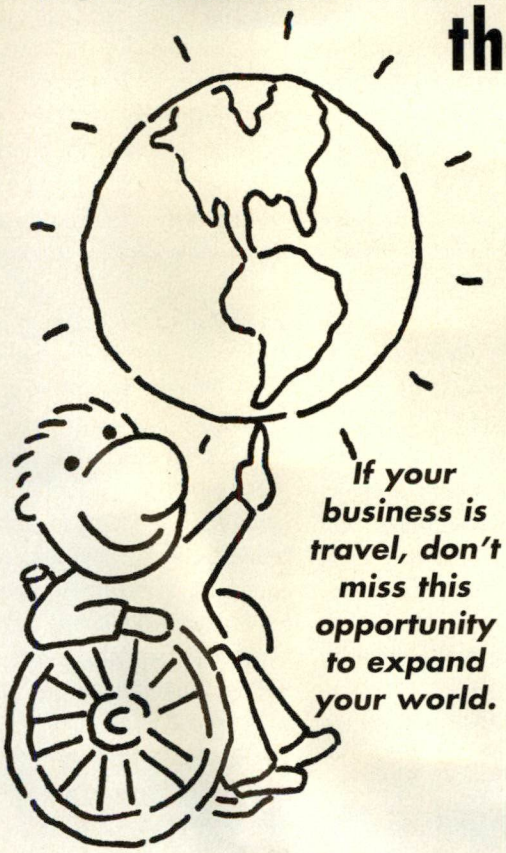
Marsha Saxton is a researcher at the World Institute on Disability in Oakland, Calif., and teaches disability studies at the University of California at Berkeley.

Women's Resources

- *ABLED!* is a quarterly newsletter for "active, beautiful, loving, energetic disabled" women. $10/year from 12211 Fondren, Suite 703, Houston, TX 77035; 713/726-1132.
- A new edition of *Bridging the Gap: A National Directory of Services for Women and Girls With Disabilities* is scheduled to be published in December. Contact Educational Equity Concepts, 114 E. 32nd St., New York, NY 10016; 212/725-1803.
- *Disabled Women: Visions and Voices* is a 13-minute video about the Fourth World Conference on Women. $18-$30 (sliding scale) from Wide Vision Productions, P.O. Box 22115, San Francisco, CA 94122-0115; 415/387-0617.

continued on page 71

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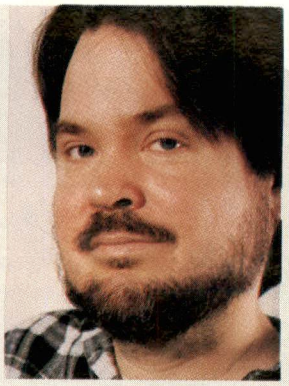
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ERVIN

Erasing the E-Word

By Mike Ervin



I had been sentenced for the crime of feeling a sense of entitlement.

The salesman on television was of the carnival-barker genre—gleaming teeth, big bow tie, loud blazer, neck veins throbbing.

"What would you pay for this amaaaaazing home security system?" He shook a stack of stapled papers in the air. "This home security system is no bigger than this stack of papers! Yet it protects you from intruders breaking into your home, kidnapping you and taking away all your possessions! Now what would you pay!" He rattled the papers furiously.

"Yes, ladies and gentlemen, it's all right here in this incredible new entitlement program! With this amazing new entitlement program, you will be guaranteed that, no matter what happens, you will never ever have to go into a nursing home! You will receive all the help and support you will ever need, right in the comfort and privacy of your own home! That's right! Never again will you have to dump your parents in some rat hole after all they sacrificed for you! Never again will you have to fear growing old or becoming disabled! Never again will you have to pawn everything you own just to hire someone to give you a sponge bath!

"Now how much would you pay!" he thundered. "Ten billion? Twenty billion? One hundred billion?"

I was all stoked up! "Yes! Yeeees!"

The salesman huffed and puffed: "What's that you say? You say you've got a severe head injury? You use a wheelchair? You can't even talk or feed yourself? NO PROBLEM! This amazing home security system works for everybody! Absolutely guaranteed! How can you get this incredible home security system? It's easy! Call the number on your screen right now! That's the number of your congressman! Call and say you want the most amazing home security system ever made! What are you waiting for? Pick up that phone right now!"

I was raging with excitement. I snatched the phone receiver and dialed. I had to have that incredible home security system now, and I didn't care how much it cost! Any price was worth it! I couldn't live without it! If only I had that incredible home security system, I could sleep well at night, knowing that little could harm me! Isn't that what we all want, I said to myself? Is this not the American dream?

The line was busy. I hung up and hit redial. Busy again. I hit redial over and over and over for hours, days, weeks. Still busy. Apparently almost everyone in America wanted this amazing home security system.

And then I suddenly woke up. The guy from the next bed was shaking me.

"Wake up!" he was saying. "They'll hear you!"

Slowly, depressing reality returned. I was an inmate at the Jesse Helms Institute for the Politically Insane. I had been sentenced here for the crime of feeling a sense of entitlement.

"You said the E-word in your sleep!" the guy from the next bed gasped. "Twice!"

"E-word?" I said. "You mean entitlement?"

"Sssssshhhhhhh!" he said. "Don't say that word!"

But it was too late. The alarms went off. That could mean only one thing. My illegal fantasy had been picked up on the screen of my dream monitor. The quick response team was on its way.

The guy from the next bed pulled the covers over his head and cowered. My punishment for regression would be swift and severe. The dream cops would take me to a cold, gray room where I would be subjected to hour after grueling hour—day after grueling day—of doing crossword puzzles. Re-education crossword puzzles, all exactly the same: 3 across: An 11-letter obscenity beginning with E meaning selfish, greedy, spoiled, un-American. 17 down: An 11-letter obscenity beginning with E meaning selfish, greedy, spoiled, unAmerican.

Soon I would again realize the central patriotic principle that makes America great: No one deserves a damn thing. NM

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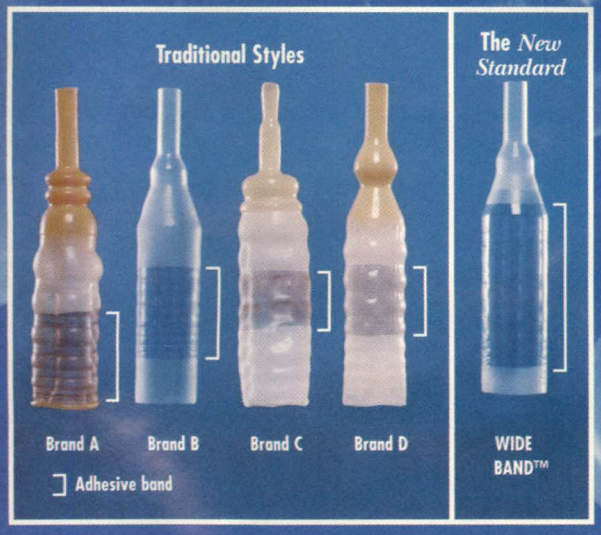
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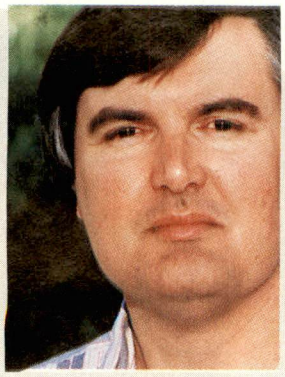
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WHEELS

The New GM Minivans

By Karl Beck



GM's Venture, Trans Sport and Silhouette all compare favorably with Chrysler's Caravan and Voyager and Ford's Windstar.

General Motors Corp., in a classic case of keeping up with the competition, has redesigned its plastic-bodied minivans into a more metallic configuration that closely resembles Chrysler's Caravan, Voyager and Town and Country. For disabled motorists, it means another vehicle that can be modified to fit their needs.

The new minivans are available with various trim packages and two wheelbase lengths—112 inches and 120 inches—but all have a 3.4 liter V-6 engine, a four-speed automatic transmission, 20-gallon fuel tank (25 gallons optional), dual front air bags and antilock brakes. GM, recognizing that it is competing with strong Chrysler products, has priced the new products competitively—complete with a $1,000 rebate applicable against the cost of adaptive modifications.

The Chevrolet Venture is a basic, practical family vehicle that can be purchased with an optional LS package adding power door locks, power windows and an upgraded radio system. The Pontiac Trans Sport is sportier and loaded with additional features, while the Montana comes with an SE trim package offering plastic side molding that resists chipping. The Oldsmobile Silhouette also has two trim levels, the GL and the GLS. Billed as a luxury vehicle, the GLS can be purchased with leather seating, CD player and all the amenities you would expect from a $30,000 minivan.

GM's Venture, Trans Sport and Silhouette all compare favorably with Chrysler's Caravan and Voyager and Ford's Windstar. The interior size is similar, wheelbases are comparable and, except for the Windstar, all offer an optional driver-side sliding door. (But note that no minivans on the market currently offer power operators on their driver-side doors.) The GM vans do have one edge: Their passenger-side sliding doors are 1 inch wider than Windstar's and 1.5 inches wider than Chrysler's, and a power-operated, remote-controlled option is available.

Most existing hand controls, steering devices and emergency brake extensions—with low-effort steering still to come—can be adapted to the GM vehicles, although no wheelchair lifts are yet available.

The Braun Corp. has adapted its Companion Seat, which helps a person load into the front passenger seat, to fit these vans. Development of this product and other special seating has been hindered by GM's placement of the electronic control boxes for the air bag sensor system.

Many of Bruno Corp.'s products will fit GM's minivans because their dimensions are so similar to Chrysler's. The Scooter Lift II, which mounts behind the driver and passenger seats, can load a scooter or power-base wheelchair into the center of the van through either the driver- or passenger-side door.

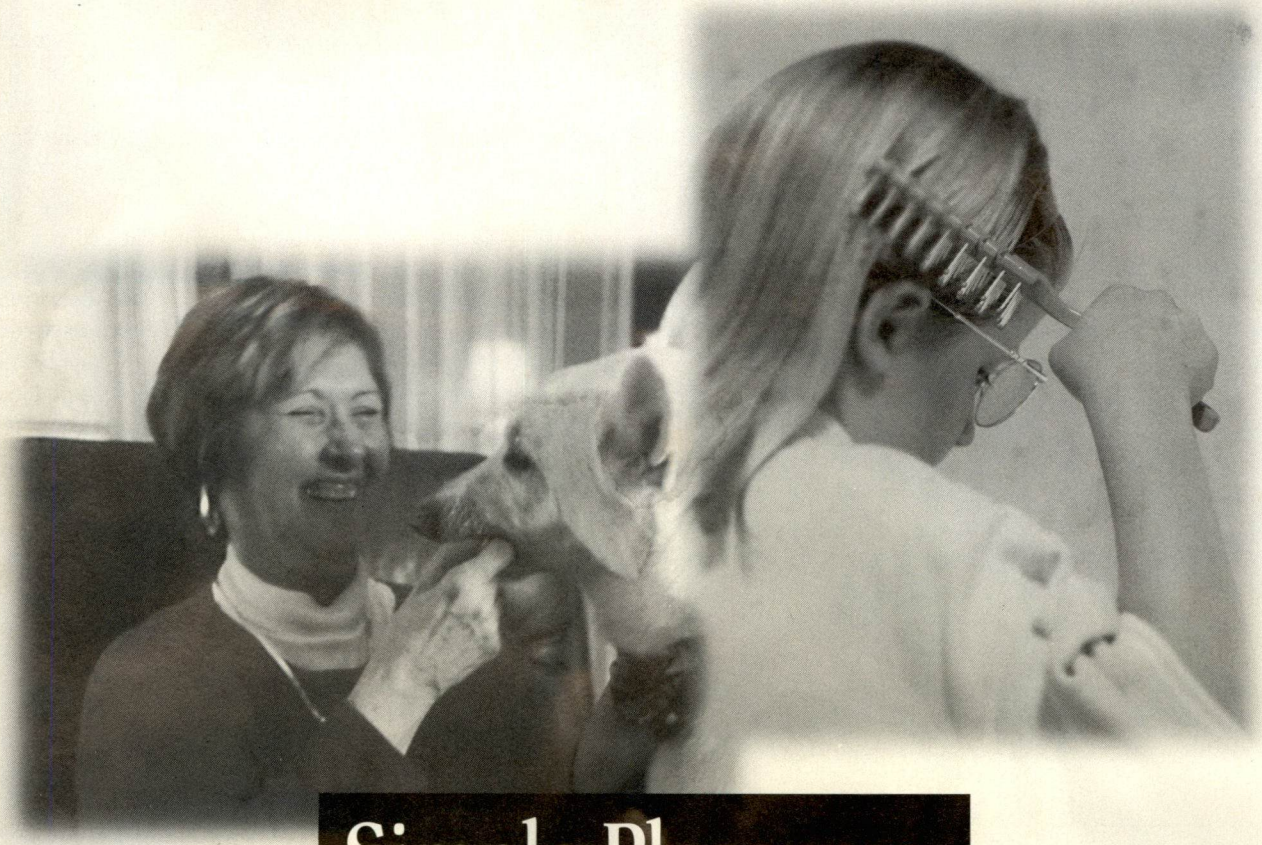
Manufacturers of lowered-floor minivan conversions also have plans to modify GM vehicles. The conversion lowers the floor and door by 8 to 10 inches, adds a ramp, and usually kneels the vehicle to keep the ramp's slope gentle. Engineering and crash-testing will take time, but Vantage, Ricon and Braun—among others—have conversions in development. Freedom One already has a modified Venture on the market. It features a 10-inch lowered floor, power ramp, power side cargo door and kneeling.



The Venture

- The Braun Corp., 800/The-Lift
- Bruno Corp., 800/882-8183
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continued from page 18

rashes. If a syphilis infection is not treated at this stage, it will again become invisible and can remain so for months or years. But if it's not treated, the consequences can be quite serious, including damage to the nervous system, blood vessels and brain.

Common viral infections include herpes, hepatitis, papilloma and HIV.

Herpes ulcers may be experienced by women with spinal cord injury as muscle spasms, sweating, headache and blood pressure changes (dysreflexia). There is no cure for herpes, but treatment can help the blisters heal faster and make them less painful and less likely to cause dysreflexia. Many women have recurrent herpes outbreaks that are preceded by a prodrome, a premonitory symptom in the location of the previous outbreak. At this point, women with sensation would take medication to prevent the recurrence, but women with sensory impairment need to develop other ways to identify a prodrome.

Some women with disabilities who were in accidents many years ago may have been infected with the hepatitis virus by blood transfusions without realizing it. Women who contracted hepatitis from transfusions, sexual contact or IV drug use should ask a physician to monitor their liver function. There is no treatment for hepatitis, but restricting toxins such as alcohol may be necessary to avoid its worst effects.

Papilloma virus is common, and women should be screened for it regularly because it predisposes them to cervical cancer. Unfortunately, women with physical limitations often do not have regular pap smears because of access issues (a future column will discuss cancer screening).

Symptoms of HIV can be extremely variable, from vague unwell feelings early on to the development of frequent and hard-to-treat infections as the immune system becomes further damaged. But again, many chronic diseases and disability states involve vague feelings of unwellness and fatigue, so women who notice these symptoms may not recognize them as related to HIV. A persistent, unusually nasty yeast infection may signal an immune system problem. Sexually active women should take an HIV test every six months if they've had more than one partner in the preceding year.

In future columns, Dr. Welner will discuss cancer screening, osteoporosis and menopause.

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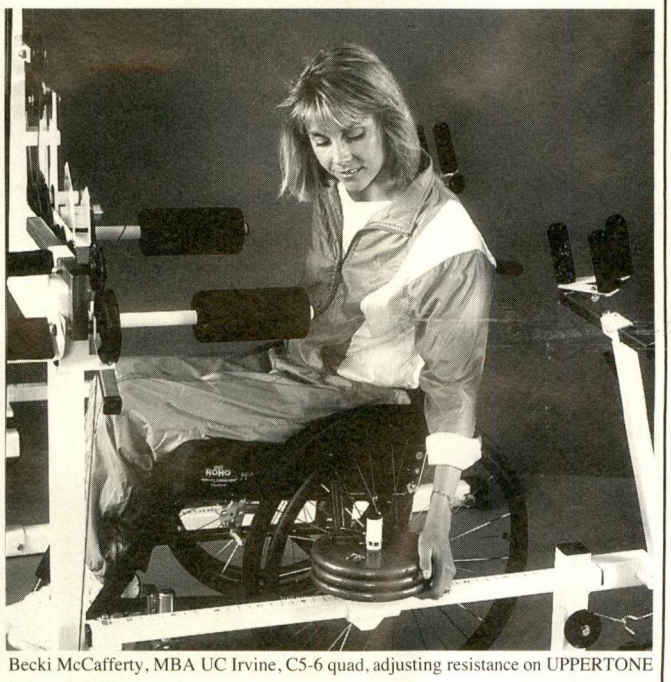
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By Mitch Tepper, Lizzi McNeff and Patti McNeff

Solo Pleasure

Before my partner and I split up, I had an active sex life. He was the only sexual partner I'd had since the onset of my disability. Now that I am on my own sexually, I am interested in masturbation but have limited hand function and hardly any trunk stability. Any suggestions?

You can tape or Velcro a cuff to a vibrator, or strap the vibrator to a long handle so you can reach your genitalia more easily. If lubrication is an issue, try Astroglide or one of the other new products on the market. You'll find vibrators and lubricants in mail-order catalogs (e.g., Good Vibrations or Xandria) or at your local adult toy store.

Since trunk stability is a concern, try propping yourself up with pillows behind your back. If you can manage it, bringing each leg up will put you in a spread-eagle position. A small pillow or rolled towel under each leg can provide additional support.

Another option is to use your wheelchair. If you use a calf strap, simply put your feet on the strap and scoot your butt forward a little. *Voila,* you are ready.

Reading (or writing) erotica, watching adult videos, self-hypnosis, pleasuring yourself in front of a mirror, and using feathers or furs to stimulate your tactile senses are all viable forms of masturbation.

—Lizzi McNeff

Worthy of Love

I have a male friend with multiple sclerosis who doesn't think he will ever attract a girlfriend because of his disability. He even says he is not worthy and whoever would want him, he wouldn't want. How can I help him?

Start by challenging his faulty thinking, because that's where his real problem lies. *All* humans are worthy of love, affection and intimacy.

At some point, most of us question our self-worth, then resolve the issue and get on with our lives. Your friend may face an extra challenge to viewing himself positively because of the real losses caused by MS, but he needs to sort out how much of his sense of unworthiness came before getting MS and how much came after.

If he views himself as too unlovable to have a girlfriend, that's what will happen. He needs to understand why he feels so unworthy, then truly accept the reality that he *is* worthy despite the challenge of his disability. This will probably require him to look at himself as a whole person, not just someone whose life has been changed by MS.

For you, it is a delicate balancing act. As a friend, you will want to be supportive, understanding and encouraging, yet not buy into his negativity. That's where an objective therapist can really help.

—Patti McNeff



Sandy L., Chicago Artist, C-6 quadriplegic

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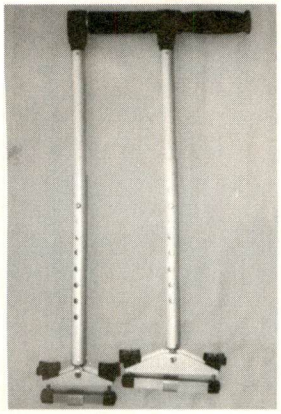
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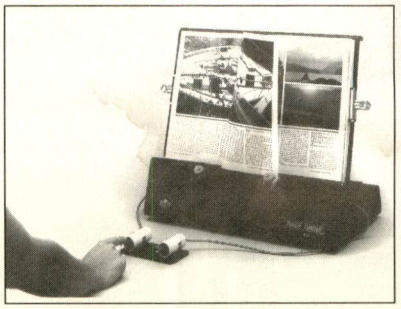
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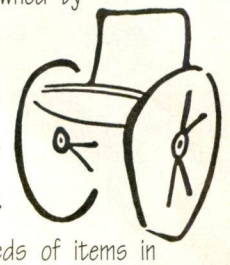
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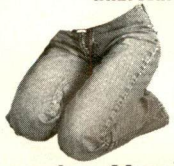
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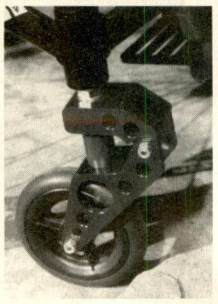
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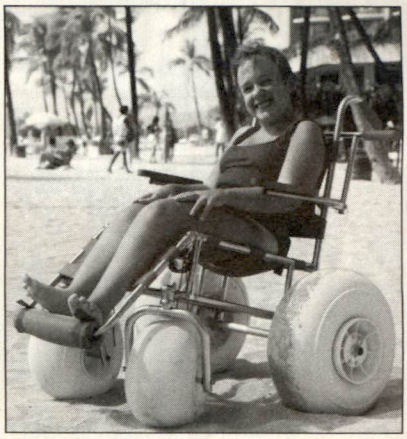
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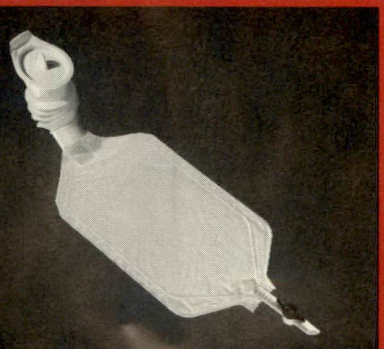
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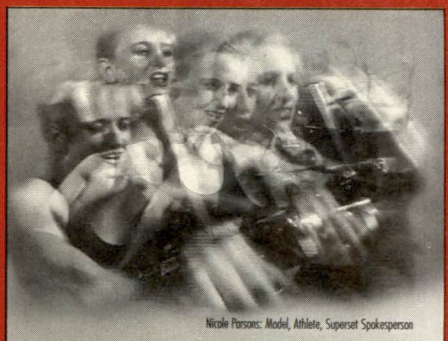
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FULL CIRCLE

HERE

by Cheryl Marie Wade



Photo by Suzanne Levine

There is a woman here
middle-aged in her prime
with long legs
and a short fuse
A woman who loves to write
poems
and dance
I have rhythm in the marrow
laughter, too
I love to laugh and laugh

There is a woman here
who has scars
visible and otherwise
more than you'd want to know
more than I want to count
A woman who believes
in magic
I long for magic
I love stones
before they're polished
I can picture Springsteen's thighs
magic

There is a woman here
with a stiff back
and incredible flexibility
who tells lies for protection
the truth for survival
who sits in a chair on wheels
and hauls sacks of self-doubt
as if she were a stevedore
A woman who survives to dream
dreams

I braid hair in my dreams

I have electric hair
and need to be loved
soft soft lips
and hate to be loved
eyes shadowed by memory
and want to be loved
full round hips
and I'm afraid to be loved
I love so easily

There is a woman here
full of colors
A survivor
who survives to be
a woman
here



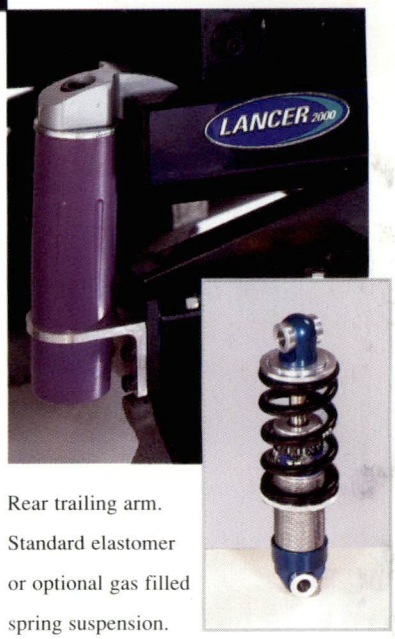
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