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FOIA MARKER

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Series:	Printed Materials
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OA/ID Number:	52132
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TIRR MIDWEEK

FORTY YEARS
TIRR
YEAR
2000
1959-1999

THE INSTITUTE FOR REHABILITATION AND RESEARCH • TIRR FOUNDATION • TIRR LIFE BRIDGE • TIRR REHABILITATION CENTERS • TIRR SYSTEMS

Customer Corner

We all work within processes and procedures. Look for ways that these processes and procedures may break down. These breakdowns then become opportunities for improvement (breakthroughs). It's more customer-oriented if we seek out and discover possible breakthroughs before they become delays in serving the customer.

TIRR is Sponsoring February 24 Bush Medal Luncheon To Honor Six ADA Advocates

TIRR is among the sponsors of the February 24 event where the George Bush Medal will be awarded to six individuals who have distinguished themselves in the movement for equal opportunity and rights for people with disabilities worldwide.

The George Bush Medal was created in 1992 by the disabled community to ensure that the work of President Bush is remembered and that the seeds of freedom which he and thousands planted will be nurtured. The purpose of the George Bush Medal is to reinforce the nation's commitment to keep the promise of the ADA to all Americans, and to encourage the spirit of the ADA throughout the world.

The awards presentation will take place at a luncheon in Houston hosted by the George Bush Medal Committee. Sponsors are TIRR, the Houston Mayor's Committee for Employment of People with Disabilities, the Health Law & Policy Institute at the University of Houston Law Center, and Continental Airlines. President Bush will personally present the awards to the four living recipients (or their representatives), and to family members (or representatives) of the two deceased recipients. Continental Airlines chairman and CEO Gordon Bethune will be the luncheon speaker, and there will be a performance by the children, some with disabilities, of The River Performing and Visual Arts Center.

Rehab Management Cover

Rehab Management magazine will feature the TIRR Pediatric Program in their next issue, with a feature story and a color cover photo taken January 19 at TIRR. The story is about Infant Seating and Mobility, and two TIRR therapists were interviewed. They are Teresa Cramer, MSPT

and Karen Ornstein, OTR, and they are pictured here with Matthew Hillman, 3, and Benjamin Nisley, 3 months, while that cover photograph was being taken. Benjamin's mother is Ann Nichols, RN and Ben is the third son for Ann and husband Tim Nisley.



We are including a biography of each of the winners in the weeks leading up to the February 24 luncheon. Here is number two in our series of six, Justin Dart, Jr., the well-known disability rights advocate. His wife Yoshiko Dart will come to Houston to accept the Bush Medal for him, because Mr. Dart is in ill health.

Justin Dart, Jr., Civil Rights for All Activist



Activism has always been a part of Justin Dart, Jr.'s life. In his college years in the early 1950's, he led an effort to integrate an all-white urban campus in Houston. Out of five students who showed up to join the "integration society," three were disabled, including Dart. That was just a coincidence, Dart

says, and at the time, they didn't think of their disability as an issue—let alone one involving civil rights.

All that was to change for Dart later in his life. Dart came from a privileged background. His father, Justin Dart, Sr., was a prominent California Republican and a successful businessman who owned the Rexall drugstore chain among others. Dart, Jr. could have easily followed the same path, but he didn't.

continued on page 2

Justin Dart, Jr., Civil Rights for All Activist *continued*

For a time, Dart became president of Japan Tupperware, a very successful and profitable venture. "I lived in a very comfortable place and had a big staff." But, after a trip to South Vietnam in 1967, in which he saw disabled children left to die in a shed, unable to move and "their bodies covered with flies," he decided to quit his business. He realized there was more to life than earning money and he wanted to discover what that was.

Dart and his wife, Yoshiko, went to live in an old farmhouse without water and electricity on a rugged mountaintop in Japan. They had no car, so when Dart couldn't get his wheelchair through the muddy roads after the rains, he would drag himself, on his hands, to the end of the road to catch a ride in to town. It was on this mountaintop, without the usual amenities of life, that the Darts "rehabilitated themselves, so they could rehabilitate others."

Now, because of his unyielding belief in civil rights and the courage to change his own life, Dart has had a great impact on the disabilities movement in the U.S.

"I came into the disabilities movement passionate about civil rights, and that's how I approached the Americans with Disabilities Act (ADA)," Dart says. "In fact, I wondered if we could sleep nights if we didn't recommend civil rights as part of the ADA."

So began an arduous battle in Washington, D.C. and throughout the country, to make the ADA, as Dart puts it, "the most comprehensive civil rights law in U.S. history." Convincing people it was needed and would work took considerable time and energy on the part of Dart and his colleagues. In his efforts to get the ADA passed, Dart visited each of the 50 states no less than five times.

Back in Washington D.C., it was the same story. Early in the battle, Dart and his colleagues were told by a White House aide that the proposed bill was "too radical" and that "The President won't touch this with a ten-foot pole." President George Bush not only fully embraced the bill, but he convinced Congress to do the same. President Bush signed the ADA in 1990.

As Dart says, "I didn't think the ADA would pass in my lifetime. It is a political miracle. The ADA has changed the attitudes of millions about people with disabilities. We have become members of the human rights movement."

On February 24, 2000, Dart will receive the George Bush Medal for his tireless efforts on behalf of the ADA. "There are lots of heroes in the picture for the passage of the ADA," Dart says. "I see myself as a symbolic representative for those who have fought over the years for people with disabilities and who haven't been recognized with this medal."

In 1998, Dart received the Presidential Medal of Freedom for his lifetime of work as a civil and disability rights advocate. This medal is the highest and most esteemed honor that a citizen can receive in this country.

Usually Dart is aware of nominations or awards ahead of time, but when President Clinton called to let him know that he had received the award, he was "caught totally off guard." Dart says, "This award pushes my sense of responsibility to others to even greater heights. I was enormously honored."

As with many advocates who must fight not only public battles, but deeply personal ones, Dart has had a tough journey to get to where he is today. From a rugged mountaintop in Japan during the 70's, to high-powered Washington, D.C. in the 80's and 90's, Dart has never lost sense of what is important.

Today Dart is still working on disability rights, but in his tenacious and passionate way, he is focusing on a broader mission. "My personal passion right now is to empower individuals—the economically, physically, and psychologically disadvantaged—as well as those who are exceptionally brilliant and talented—to overcome barriers and make the most of their God-given potential."

For the past 20 years, the Darts have opened their home to about 80 people, mostly Japanese, to help them live enriching and economically satisfying lives. Dart has created an "individual package" of educational, medical, and economic support which helps a person focus on his or her strengths and compete at a level previously reserved only for their "successful, more powerful peers."

As enduring as Dart's lifework, are his recent contributions to the Smithsonian Institute's exhibition of disability rights—the pen given to him by President Bush after the signing of the ADA, and his cowboy hat and "old worn" boots.

Dart's boots, which will be hard to fill in the coming generations, are a symbol for those who dare to stand up for what they believe—as Dart has and always will.

And Another Thing...

Microsoft Training Manuals in TIRR Library

The following ten (10) computer training manuals are now available in the TIRR Library for checkout. These manuals are perfect for the self-starters out there who can't attend classes!

Outlook:	Beginning & Advanced
Word:	Introduction & Intermediate
Excel:	Introduction & Intermediate
Access:	Introduction & Intermediate
PowerPoint:	Introduction & Advanced

Printing Center: At Your Service

Whenever you have any problem with the copiers, fax machines or are in need of paper for your office please call **the Printing Center at 713-797-5974**. When Bruce French is out of the office (as published in the MidWeek) the following procedure should be used between the hours of 7 a.m. and 3 p.m.

Copier Coverage

- Copier on floor one by the TIRR Library, toner is kept in the Library. If service is needed **Pam Cornell** will call for service.
- Copier on floor two by Patient Accounts, extra toner is kept in the room. If the machine is not working properly please **contact Ray Acosta** in Patient Referral extension 5942. He will arrange for service.
- Copier on the fifth floor equipment room, for toner or equipment malfunction please call **Janiece Mathews** at extension 7358.

For any paper needs please call Materials Management at extension 7033.

Volunteer Happenings

- The volunteers invite you to come out to the **Greenhouse** area to see the beautiful "habitat" they have created. We urge all of our therapists to bring their patients out to just "be" in this green space, and also to plant and propagate flowers, herbs and green things. The habitat that we are creating will be in full bloom in the spring. The flowers and shrubs will attract wild birds, butterflies, lady bugs, alligators, (sorry, just kidding), and will become a place of fragrance with sights and sounds to be enjoyed by all.
- The first **Blood Drive** of the year will be on **Friday, February 25**, in PDR A & B, and will go from 10 a.m. to 5:30 p.m. This will be a "double red cell" drive, and we hope that you will make every effort to donate your blood. As you probably know, there is a critical shortage of blood right now, so your help is even more important and valuable. As a small incentive, we're offering a \$3 Meal Ticket to all donors.

Looking for Camera

Volunteer Services loaned out an Instamatic camera and it hasn't been returned. If anyone has seen it, or has it, please bring it back to the Volunteer Office.

AETNA Meetings

We are currently holding monthly meetings to assist TIRR Systems employees, who are having problems with unpaid AETNA health claims, unresolved questions and/or any other issues related to health insurance. Come and meet with Paula McIntyre, our liaison from Madison Benefits Group and Donna Kisse from Aetna.

LOCATION: TIRR/TIRR LifeBridge Site,
1333 Moursund
Private Dining Room A
TIME: 11 a.m. - 1 p.m.
DATES: Thursday, January 27
Thursday, February 24
Thursday, March 23

Texas Medical Center Construction Announcements:

Garage 5 and Garage 6 Elevators

Modernization of elevators in Garages 5 and 6 will start on January 24, and end July 13. One elevator in each garage will be done at a time. These elevators will be barricaded off on each floor and will be out of service for approximately 12 weeks. Upon completion of the first two cars, we will be moving to the adjacent cars for the next 12 weeks.

Service Pipes on Fannin

LOCATION:

Fannin Street - Sections of Fannin Street between North MacGregor and Holcombe Blvd. will be closed to traffic at nights.

TIME:

7 p.m. to 5:30 a.m., Monday, January 24 for approximately nine weeks.

DESCRIPTION OF ACTIVITY:

METRO's contractor will begin the installation of underground service pipes for the new 24" water main crossing Fannin Street in 30 locations between North MacGregor and Holcombe Blvd. Fannin Street through traffic will be detoured using Main Street.

For further information or assistance, please contact Larry Weppeler, Jones & Carter, Inc. (713) 777-5337; Tommy Artz, METRO, (713) 739-4049; or Kelly Hodges, METRO, (713) 739-4007.

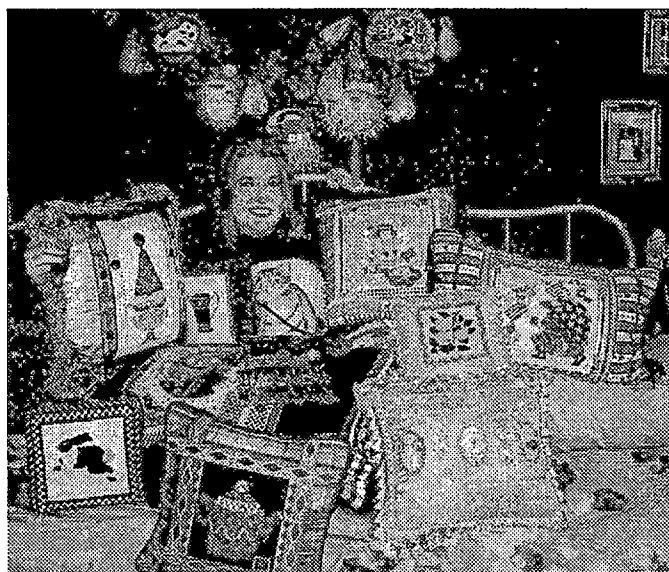
Accolades & Acknowledgments

Kathleen DeSilva, TIRR Systems, Risk Management/ In-House Counsel, appeared in a major article in the December 9, 1999, *Rice News*, pp. 4-5. Copies available in the TIRR Library.

Laura Wiggs, PT and Gerard Fransisco, MD gave presentations on "Spasticity Management" at the Medtronics conference on *Advanced Application of Intrathecal Baclofen* in Laguna Beach, CA on January 14 & 15.

Little Bits

Cynthia Card, MOMT, PT, Facility Director, TRC-Town & Country, is pictured buried with her needlepoint work. "I have been doing needlepoint since I was 10 when my mother taught me." Cynthia will be teaching basic needlepoint techniques on March 11 at Chandail Yarns, 2015 W. Gray in River Oaks shopping center. The project will be an Easter door hanger. Stop by or call Ruth Chow, 713-524-6942 to get more information or make a reservation to take the class!



Board Games Needed at the TIRR Challenge Program. Please drop your donation either at the TIRR Challenge Program, the TIRR Switchboard, or Human Resources. If you have questions please contact phone or e-mail **Caesar Pulido 713-669-1100.**

Shuttle Changes in TMC... If you need copies of these new routes please stop by Human Resources or call 713-797-5247 to have a copy sent to you.

Birthdays Across TIRR Systems

January 26 - February 1

Jan. 26	Dayna Boatright, PCU-6
Jan. 26	Benjie Collins, LifeBridge Nursing
Jan. 26	Teleola Majors-Fagbohun, LifeBridge Nursing
Jan. 26	Gail Lofton, PCU-3
Jan. 27	Arleen Vaughn, PCU-5
Jan. 27	Robyn Givens, TIRR PT
Jan. 28	Diane Roy, TIRR PT
Jan. 29	Simon Guajardo, TIRR TOTS
Jan. 30	Warren Williams, Maintenance
Jan. 31	Tajauna Hearne-Newton, Patient Escort
Feb. 1	Kelly Colmer, MIS
Feb. 1	Valerie McCraw, LifeBridge 4

Food For Thought

By Carolyn Wyly, RD, Beth Ann Fortz, RD, Johanna Mazoch, RD

Tips To Boost Nutrition

Last of the no-brainer ways to boost nutrition – next week a quiz to test your nutrition IQ!

1. Mix whole grain cereal in with your favorite flakes. You don't have to give up your beloved Rice Krispies. Simply mix a high-fiber cereal in with them. Choose one made from whole grains, which contain antioxidants and have been shown to reduce the risk of cardiovascular disease as well as certain cancers.
2. Add extra garlic and onions to your favorite prepared sauce. Don't be deterred because Mr. Newman decided not to include them. Garlic and onions are rich in sulfides, compounds known to decrease the tendency of blood clots to form, lower total and LDL cholesterol levels and decrease the risk of many cancers. Red onions also contain quercetin, another compound associated with cancer prevention.
3. Nibble nuts as a snack, or toast them and sprinkle onto salads or pasta. Forget your fat phobia for once. Almonds, cashews and peanuts are rich sources of phytosterols, substances that may lower cholesterol and that show anticancer activity in animal studies. Nuts, particularly almonds, are also a rich source of vitamin E, a disease-fighting antioxidant lacking in the American diet. Besides, these nutritional nuggets

contain unsaturated fat, the kind that helps keep HDL cholesterol levels healthy and aids in the absorption of vitamins A,D, E and K.

4. Scoop soy protein isolate into smoothies or even into orange juice. One-half cup of soy protein isolate (found in most health food stores) contains a hefty 46 grams of protein and 8 milligrams iron. Research suggests that consuming 25 grams of soy protein per day can help lower blood cholesterol levels in people with elevated cholesterol and may help reduce the risk of heart disease. Soy also may minimize symptoms of menopause such as hot flashes, and increase bone density in postmenopausal women.

That's Life

We all take different paths in life, but no matter where we go, we take a little of each other everywhere.

- Tim McGraw

Microsoft Outlook Tip of The Week: Stop Scrolling Left to Right

It's pretty frustrating working in a document and having to scroll left to right to read the lines of text. Word does have many alternatives for you to use to change this. Below is one tip to help.

The easiest Tip is to alter your Zoom Magnification to an appropriate view—like maybe 88%. Once you know it, you can create new documents that will always open to this magnification. This doesn't work for already created documents, you will have to set them each time you open them up. Here's how to set all future documents.

- Open any exiting document and use it to determine your appropriate Zoom Magnification percentage.
- Use the Magnification window located at the top of your screen to the far right on the Standard Bar (the one with all the speed buttons).
- Left-click once in the window to highlight the percentage (usually its100%)
- Enter a lower percentage (say, 90%).
- Press the Enter key. Your document's magnification will change. Continue to lower the percentage until you no longer need to scroll left to right.
- Once you have found your "Golden Percentage" number, remember it!!!
- Close the document and shut down Word.
- Wait and count to three (one Mississippi, two Mississippi, three Mississippi).
- Open Word. Boom, the new blank document before you will be set at your Golden Percentage ready to receive your words.

Now the Tricky stuff!!! To **keep** your Golden Percentage, the last document you close for the day must be magnified at that percentage...if not, Word will open the next time at the percentage of the last viewed document.

Next week, another tip on viewing your documents.

Note: A collection of all the Microsoft Tip of The Week are located at Microsoft Outlook Public Folders\All Public Folders\Global Training\Training Information.

Quotes from Steven Wright

- Do Lipton employees take coffee breaks?
- How much deeper would oceans be if sponges didn't live there?
- Ever wonder what the speed of lightning would be if it didn't zigzag?
- If a cow laughed, would milk come out her nose?

-Thanks to Connie Pepin, TIRR Systems Accounting for the submission.

In-Services To Attend

Mandatory in-service for clinical staff...Mark your calendar's now!!!

Advance Directives - Changes in Texas Law

DATES:	Wednesday, March 1
TIME:	12Noon - 1 p.m.
LOCATION:	Conference Room 2A & 2B
NOTE:	This presentation will be video taped for those not able to attend during scheduled time. The Program Educators will be posting information for the nursing employees on each unit.

ARISE Brown Bag - This Friday

A Brown Bag inservice is scheduled for Friday, January 28, from 12Noon to 12:55 p.m. in Conference 2A. To register, please contact Rennie Swift. Bring your lunch.

The University of Texas-Houston School of Nursing, through its Center On Aging Department, has developed

a new program for TIRR Systems employees who require help with their elder care needs. This program is called **ARISE**, which stands for **Aging Resource Information Support and Education**, and it provides the following:

- Aging care management
- Resources for distant relatives and caregivers
- Information on elder care issues
- Consultation and counseling for individuals or family regarding elder care issues.
- Support services
- Educational services

CPR, Mandt, and Computer Registration

REGISTRATION: You may register to attend a CPR, Mandt, or Computer (Word or Outlook) class by one of the following methods: PHONE: 713-797-5247; FAX: 713-797-5245; E-MAIL: Rennie Swift; POST: Post a copy of an Attendance List in Outlook Global Training folder. Attendance Lists for CPR, Mandt, and Computer classes can be found, when in Microsoft Outlook, by opening Folder List, then double-clicking Public Folder, then All Public Folders, then Global Training.

CPR

DATES: Monday, February 7
TIME: 3:30 p.m. - 7:30 p.m.
LOCATION: Conference Room 2A

DATES: Friday, February 11
TIME: 10:30 a.m. - 2:30 p.m.
LOCATION: Private Dining Room A/B

DATES: Monday, May 15
TIME: 3:30 p.m. - 7:30 p.m.
LOCATION: Conference Room 2A

DATES: Friday, May 19
TIME: 10:30 a.m. - 2:30 p.m.
LOCATION: Conference Room 2B

Mandt

1-Day Mandt Recertification

Times: 8 a.m. - 4:30 p.m.

<u>Date</u>	<u>Location</u>
Tuesday, February 1	Private Dining A
Friday, March 10	Private Dining Room A&B
Wednesday, March 29	Private Dining Room A&B

2-Day Mandt Recertification

Times: 8 a.m. - 4:30 p.m.

<u>Date</u>	<u>Location</u>
Thursday-Friday, February 24-25	Conf. Rm 2B
Monday-Tuesday, March 20-21	TBA
Thursday-Friday, April 20-21	Conf. Rm 2B
Monday-Tuesday, May 22-23	Conf. Rm 2A

Microsoft Word & Outlook Training Jan.- March

<u>Date</u>	<u>Day</u>	<u>Time</u>	<u>Loc</u>	<u>Topic</u>
2/4	Fri.	8:30 a.m.-12N	2C	Word: Beginning
2/21	Mon.	12:30 p.m.-4:30 p.m.	2C	Outlook: Basic
2/22	Tues.	12:30 p.m.-4:30 p.m.	2C	Word: Intermediate
3/17	Fri.	8:30 a.m.-12N	2C	Word: Beginning
3/24	Fri.	8:30 a.m.-12N	2C	Word: Intermediate
3/27	Mon.	12:30 p.m.-4:30 p.m.	2C	Outlook: Advanced

Your MidWeek Team

Contributors: Everyone Working at TIRR Systems
Editor: Rennie Swift (713-797-5247)
Graphics/Printing: Bruce French (713-797-5974)

Submissions to the TIRR MidWeek are due by noon the Monday before each Wednesday's issue. Submissions may be sent to Rennie Swift, Human Resources (O-101), PhoneMail at 713-797-5247, or FAX at 713-797-5245, and e-mail!

TIRR MIDWEEK

FORTY YEARS
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Out Of Office

Dr. Kathryn Zidek, Out: Until April 10. Brain Injury inpatient coverage: Dr. Ivanhoe/Dr. Francisco. Spinal Cord Injury inpatient coverage: Dr. Donovan/Dr. Parsons. Brachial Plexus patient coverage: Dr. Ivanhoe. Dr. Zidek's resident is available by pager at (713) 833-7456. Please contact Theresea at ext. 5052 if you have questions.

Physicians Call Schedule

January

DATE	FIRST CALL	ADMIN. CALL
Wednesday, 1/26	Dr. Puig	Dr. Lai
Thursday, 1/27	Dr. Lehman	Dr. Francisco
Friday, 1/28	Dr. Carranza	Dr. Tran
Saturday, 1/29	Dr. Fuoco	Dr. Tran
Sunday, 1/30	Dr. Lehman	Dr. Tran
Monday, 1/31	Dr. Panganiban	Dr. Lai

Resident's Beeper Numbers - January

5 p.m. - 8 a.m. On Call Pager Number - 713-919-4366

Dr. Fuoco,	(Zidek)	713-833-7456
Dr. Arcedo,	(Francisco)	713-833-8289
Dr. Lehman,	(Donovan)	713-833-9880
Dr., Panganiban	(Parsons)	713-891-5681
Dr. Carranza,	(Ivanhoe)	713-833-8460
Dr. Lord	(Khalifa)	713-833-9391
Dr. Puig	(Tran)	713-833-8391

Plastic Surgery or Baclofen Pump Issues

Contact: Lalita Thompson RN at ext. 5741 pager 713-833-9293.

TIRR **MIDWEEK**

November 15, 2000

LEADING THE WORLD
IN REHABILITATION

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Lex Frieden Elected President of Rehabilitation International

The 90-country governing assembly of Rehabilitation International (RI), meeting at the organization's quadrennial World Congress in Rio de Janeiro, Brazil this summer, elected Lex Frieden of TIRR its president for the next four years. Frieden is only the second person with a severe disability to be selected for the presidency of RI.

Frieden, a disability rights advocate, is Senior Vice President of TIRR (The Institute for Rehabilitation and Research) and Professor, Physical Medicine and Rehabilitation, Baylor College of Medicine. He is a nationally recognized leader of the independent living movement by people with disabilities, and was awarded the prestigious Henry B. Betts Award at the Library of Congress in Washington in October 1998.

RI is a federation of 200 national and international organizations and agencies in 90 countries. Its work centers on the rehabilitation of people with disabilities, and the equalization of opportunities for persons with disabilities and their families within society. The organization, founded in 1922, is one of only five disability-focused non-governmental organizations in the world to have consultative status with the United Nations.

In his new position, Frieden will meet with government and organization officials and with heads of state in countries around the world. "It is my intent to work in harmony with international human rights groups and other disability organizations to secure the adoption of a United Nations Convention on the rights of people with disabilities," Frieden said. "I also want to expand the reach of Rehabilitation International by including more representation from poor and developing countries, and I plan to assure the long-term viability of the organization through the establishment of a perpetual endowment."

Frieden has been a powerful advocate for people with disabilities since he was injured in a car accident while in college. He is a member of the United Nations Panel of Experts on the Standard Rules for Disability. He is the founder and director of TIRR's Independent Living Research Utilization (ILRU) Program. From 1984 to 1988 he served as executive director of the National Council on Disability, an independent federal agency located in Washington, D.C. In that capacity he was instrumental in conceiving and drafting the ADA.

TIRR Employee of the Season!

Congratulations to **Annette Clark**, TIRR Admissions, for being selected **Employee of the Season**. Annette received the news at the Employee of the Season reception held at the TIRR dining room, Friday, November 10. Look for her story in a future TIRR MidWeek.

TIRR Vision

**Leading the World In
Rehabilitation**

OpEd Piece Written By TIRR Systems President Ashley Smith in Nov. 13 Houston Chronicle

An article written by **TIRR Systems President and CEO Ashley Smith** appeared in the Monday, November 13 Outlook (editorial) section of the Houston Chronicle. The headline: "There is hope after central nervous system injuries." The piece appeared in conjunction with the Thursday (November 16) gala "TIRR Gala 2000: I Believe I Can Fly" to benefit Mission Connect, the TIRR-led research consortium of medical schools. The focus of the article is why TIRR is best positioned to make Houston and the Texas Medical Center the place where the "cure" will be found.

The article, in its entirety, is located in the Global MidWeek folder in Microsoft Outlook *Public Folder/All Public Folders*.

Election Day at TIRR

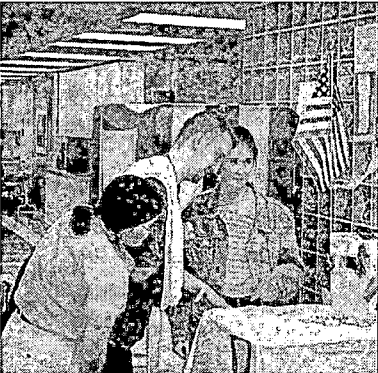
by Erin Henry, TIRR OT

Election Day, November 7, 2000: A day everyone in America will remember, even those in the hospital, especially TIRR hospital. The Occupational Therapy Department held our own election with voting booths, sign-in, ballots and poll takers. Our group was set up to encourage function, motivation, participation, education, and just plain fun. Patients from the SCI, TBI, CompRehab, and Pediatric units participated in casting their votes. The ballot included 5 items: 1) the presidential race, 2) the Olympic and 3) sports arena propositions, 4) a question asking if the name "Texans" was a good choice for our NFL team and 5) last, but possibly most difficult: "what is the best side dish for Thanksgiving dinner?"

After voting and receiving an 'I voted' button a post election commentary took place. Information and education was provided from **Kristy Davidson, LMSW** on ADA, voting and accessibility; a patient shared voting trivia information, and a question/answer session took place.

Oh, and the results! Well, re-counts are still taking place. Seriously, Bush defeated Gore by 1 vote, the Olympic and sports arena narrowly passed, Texans was voted as a good name, and Stuffing won hands down and will now be 'incumbent stuffing' in the next election!

Thank you to all therapy staff who brought patients and assisted with the election.



Laura Wiggs, PT helps patient, Jeremy Cline, put his vote in the ballot box.

Patient Elizabeth McLaughlin makes her vote count!



Erin Henry, OT asks patient, Willie Lewis, "Have you ever had this much fun voting?"

Flu Shots Are Going To Be Late!!!

by Betty Clark, RN, HR Specialist/ Occupational Health Nurse

Please be aware that the Flu vaccine is delayed coming from the manufacture. I spoke with Pharmacy today and they hope to have it by early December. I suggest to call your Doctor if you feel you can not wait until December. Any further questions please call me at 713-797-5263.

ESW/Employee Safety and Wellness Committee Wellness Awareness Lunch Time Special

Mark your calendar for **Monday, November 20**. ESW will be offering information and mini presentations for your good health.

Starting at 11:00 am until 1:30pm at the cafeteria entrance you may:

- Have your Blood Pressure checked
- Learn the Diet Blood Pressure connection
- Hear the latest on Diabetes
- See how to better protect your back
- See posters and watch your e-mail for more details

Many Contribute at 62nd AAPM&R Assembly

TIRR, Baylor PM&R and UT PM&R contributed significantly at the 62nd Annual Assembly of the American Academy of Physical Medicine and Rehabilitation, November 2-5, in San Francisco, California. Listed below are those contribution:

Course

Pain Rehabilitation: Implantable Technologies for Pain Control: Appropriate Indicators for Treatment Guidelines

Course Director: **Martin Grabois, MD**

Course

Brain Injury: Update on Prognosis and Pharmacologic Management for Vegetative/Minimally Conscious Patients

Speaker: **Cindy Ivanhoe, MD** "The Pharmacologic Management of Vegetative/Minimally Conscious Patients"

Course

Rehabilitation Topics: Overview of Acupuncture Theory and Research

Course Director: **Martin Grabois, MD**

Course

Brain Injury: Management of Spasticity

Speaker: **Cindy Ivanhoe, MD** "Intrathecal Baclofen Therapy for Spasticity"

Paper Presentations

Prospective Study on the Use of Bolus Intrathecal Baclofen for Spastic Hypertonia Due to Stroke by **Samuel P. Grissom, Maria Tolotta, Cindy Ivanhoe, MD, Tony Chin, Bhumes Dihenia**

Poster Presentations

Incidence of Abnormal Muscle Tone and Spasticity During Acute Traumatic Brain Injury Rehabilitation by **Thu Le, Ben N. Nguyen, Madhuri Motaparthy, Gerard Francisco, MD**

Effects of Intrathecal Baclofen Therapy on Walking Speed of Individuals with Poststroke Spastic Hemiplegia by **Gerard Francisco, MD**

Effective Dosing of Intrathecal Baclofen in Spasticity Associated with Cerebral Palsy and Spinal Cord Injury by **Angelica Carranza, Kathryn Zidek, MD, Gerard Francisco, MD, Daniel Graves**

Successful Management of Posttraumatic Hemiballismus with Intrathecal Baclofen by **Gerard Francisco, MD**

Hydrocephalus Following Traumatic Brain Injury: Incidence, Risk Factors and Outcome by **Corwin Boake, PhD, Stuart Yablon, MD, Cindy Ivanhoe, MD, Flora M. Hammond, Ross D. Zafonte**

Does Electric Stimulation of Spastic Muscle Prior to Botulinum Toxin Injection Improve Outcome in Spasticity Management of Patients with Traumatic Brain Injury? by **Cindy Ivanhoe, MD, Naveen Ramineni**

Comparison of Stochastic Resonance Enhanced Versus Conventional TENS Treatment in Patients with EMG Documented Radiculopathy by **Benjamin N. Nguyen, Thao Tran, James Song, Donna Bloodworth, Faye Chiou Tan**

Early Rhabdomyolysis in Intrathecal Baclofen Withdrawal: A Case Report by **Kathryn Zidek, MD**

Effects of an Aggressive Standing Protocol on Bone Density in Chronic Pain Cord Injury by **J. Glen House, Jenny M. Lai**

Mrs. Hoolsema's Key Lime Pie

Mrs. Ruth Hoolsema, a patient on LB3, has submitted a great recipe for everyone to try. Sounds like a tasty to share!

Key Lime Pie

Mix together:

- 2 cartons lime yogurt
- 1-4oz box lime Jello (dry)
- 8 oz carton Cool Whip

Put mixture in graham cracker crust and chill until firm. Great!!

The Christmas Cookie Share-Along is Back! – Thursday, December 14, 11:30am - 1:30pm

The 7th Annual Christmas Cookie Share-Along is right around the corner and we need your participation.

The Cookie Share-Along is easy. Just throw together 2, 3 or 4 dozen of your favorite cookies and bring them to the **Division of Education**,

B-107 on Thursday, December 14 before 10am. As in years past, members of the Division of Education will station themselves outside the TIRR cafeteria from 11:30 a.m. - 1:30 p.m. offering complimentary cookies, wassail, Christmas music and good cheer to all who pass by.

If you wish to donate cookies, please contact **Pam Cornell** at **x5947** with your name. Then, come by the cafeteria Thursday, December 14 for your fair share! Some of the recipes will be published in future MidWeeks and your recipe could be chosen for publication. This is a great TIRR tradition and we want you to be part of it.

MidWeek Survey Winners

The winners of the MidWeek Survey are:

- **Julie Keller - TIRR PT** First to Submit a survey
- **Patrick Fields - TRC-CSC** The middle to Submit a survey
- **Nicole Miranda - TIRR TOTS** Last to Submit a survey

Each will receive a \$15 gift Certificate to Barnes & Noble. Great!!

Thanks to everyone for contributing your feedback. The MidWeek Team will review them and make every attempt to shape the MidWeek to your needs.

YOU Can Ride a Vanpool and save \$\$\$ and your car.

Need riders to Texas Medical Center from Pasadena Deer Park, LaPorte, and Baytown. Meet just one (1) block of Highway 225. For saving information and details contact: Linda Spain 832-824-2271 or Blanca Zarate 713-798-6523

TIRR Mission:

- Create partnerships
- Exceed expectations
- Excel in care
- Optimize resources
- Provide value
- Research for breakthroughs
- Serve the community
- Share knowledge
- Unleash potential

Schedule for Open Enrollment Informational Meetings

Representatives from Human Resources, Madison Benefits Group (MBG) and Aetna will be available at all of the following times and locations. If you have questions or are considering any type of change of coverage, be sure to come by and talk with Donna, our AETNA representative and Paula from MBG. Madison Benefits Group will be acting as the service liaison on behalf of TIRR Systems with the various insurance carriers.

OPEN ENROLLMENT SCHEDULE

November 15 until November 30

Deadline for turning All forms into the HR department is December 1.

Wednesday, 11/15	11:30am-12:00noon	TIRR Site - PDR - B
	12:15pm-12:45pm	TIRR Site - PDR - B
	12:30pm-1:30pm	TRC-Greenway (Lunchroom)
	1:00pm-1:30pm	TIRR Site - PDR - B
	1:45pm-2:15pm	TIRR Site - PDR - B
	3:15pm-3:45pm	TIRR Site - PDR - B
	4:00pm-4:30pm	TIRR Site - PDR - B
Friday, 11/17	7:00am-7:45am	TIRR Site - Activity Room 6A
Saturday, 11/18	2:00pm-2:30pm	TIRR Site -5 Floor Activity Room
	2:45pm-3:15pm	TIRR Site -5 Floor Activity Room
	7:30pm-8:00pm	TIRR Site -5 Floor Activity Room
	8:15pm-8:45pm	TIRR Site -5 Floor Activity Room
Tuesday, 11/28	7:00am-7:45am	TIRR Site - Activity Room 6A
Thursday, 11/30	3:15pm-4:00pm	TIRR Site - PDR - B
	4:15pm-5:00pm	TIRR Site - PDR - B

COMPLIANCE is everybody's business

We want to do business the right way. Be mindful of:

- Patient abuse or neglect
- Confidentiality
- Proper documentation/billing procedures
- A safe environment
- Conflict of interest

**Talk to your supervisor
if you have a question.**

**The Compliance Hotline
Phone number is
(713) 942-6180**

Out Of The Office

Other off-site locations will be handled one-on-one as requested.

Betty Clark, Human Resources, Out: Wednesday, November 15 through Friday, November 17, and Wednesday, November 22. OJI Coverage: Gail Sims (Pager 713-833-7682). Float Pool or Agency Coverage: Sandy Young.

Physician's Call Schedule

DATE	FIRST CALL	ADMIN. CALL
Wednesday, 11/15	Dr. LaTorre	Dr. Donovan
Thursday, 11/16	Dr. Hartman	Dr. Zidek
Friday, 11/17	Dr. Fadia	Dr. Tran
Saturday, 11/18	Dr. Le	Dr. Tran
Sunday, 11/19	Dr. LaTorre	Dr. Tran
Monday, 11/20	Dr. Alea	Dr. Ivanhoe
Tuesday, 11/21	Dr. Reneau	Dr. Lai
Wednesday, 11/22	Dr. Le	Dr. Zidek

Resident's Beeper Numbers - November

5 p.m. - 8 a.m. On Call Pager Number - 713-919-4366

Dr., LaTorre	(Zidek)	713-833-7456
Dr. Hartman,	(Francisco)	713-833-8289
Dr. Fadia,	(Donovan)	713-833-9880
Dr. Alea	(Parsons)	713-891-5681
Dr. Reneau,	(Ivanhoe)	713-720-2672

Note, this is a new pager number

Dr. Le, S.	(Dr. Kaldis)	713-891-2127
Dr. Hu	(Dr. Kothari)	713-833-8289
LifeBridge Dr. Hartman	(Dr. Kaldis)	713-891-2127

Plastic Surgery or Baclofen Pump Issues

Contact: Lalita Thompson RN at ext. 5741 pager 713-833-9293.

Year 2000 Goals

Excellence in partnership with Physicians
Inpatient capacity expansion
Making TIRR Systems "The Best"
Mission Connect

State Initiatives *in* End-of-Life Care

Issue 24, April 2005

Focus: Diversity and Discrimination

Policies to Address Disparities in End-of-Life Care

In this image, a caregiver from Zuni Home Health visits with a patient. Zuni Home Health provides culturally appropriate care to a Zuni, Navajo, and white population in New Mexico. Americans who are diverse in terms of their race, ethnicity, class, sexual orientation, disability, or geography often get less health care or substandard health care, and have worse health status than other Americans. They may be suspicious of mainstream medical care and find it hostile to their beliefs and needs. Policy changes that focus on ensuring access, mandating and funding training for caregivers, resolving legal issues related to treatment decisionmaking, and adequately reimbursing caregivers and institutions could help more Americans access adequate care at the end of life.



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Diversity and Discrimination: Gaps in Care and Policy

Americans from diverse populations are less likely to have access to medical services, may face discrimination, and may not be understood by care providers. Patients may be marginalized by race or ethnicity, sexual orientation, disability, income, or geography. Unfortunately, these Americans face barriers not only to general medical care but to adequate end-of-life care. They suffer needlessly at the end of life all too often.

There are three kinds of barriers to their care:

Access. People from diverse populations often lack access to medical care because they don't have insurance or the insurance they have requires high copayments and deductibles. In addition, there may not be primary care providers in their communities.

Trust. They may not trust the medical establishment, which has often ignored or dismissed them and, in the case of the U.S. Public Health Service study of syphilis in black males, abused their trust and ensured suffering and death.

Training. Medical care providers lack the training, knowledge, resources, and policy that would support them as they work with diverse populations.

It is not easy to address such profound difficulties in American society, since they permeate institutions and individuals and since many of the policy solutions will require additional funding. Nevertheless, the scale of human suffering is large and growing, as poverty and the number of uninsured people increase.

Policy changes that focus on ensuring access, mandating and funding training for caregivers, resolving legal issues related to treatment decisionmaking, and adequately reimbursing caregivers and institutions could help more Americans access adequate care at the end of life.

"The entire history of health care in the United States has been shamefully blighted by a long series of racial inequalities. As a result, a legacy of distrust has been handed down from one generation to the next."

Remembering Marian Gray Secundy

This issue of *State Initiatives in End-of-Life Care* is dedicated to the memory of Marian Gray Secundy, PhD. A professor emeritus of bioethics at Howard University Medical School, Dr. Secundy worked her entire life to address racial injustice in the medical establishment. She devoted particular attention to ensuring that people of color could have access to adequate care at the end of life.

From 1999 until her death in 2002, she was the director of the new Tuskegee University National Center for Bioethics in Research and Health Care, formed two years after President Clinton apologized for the syphilis study conducted from 1932 to 1972 by



Marian Gray Secundy
1938–2002

the U.S. Public Health Service on African American men from Macon County, Alabama. Scientists studied the development and progression of syphilis in these men without telling them that they had the disease and without telling them that they could be treated and cured. "The entire history of health care in the United States has been shamefully blighted by a long series of racial inequalities," Dr. Secundy said. "As a result, a legacy of distrust has been handed down from one generation to the next."

Dr. Secundy served on the National Advisory Committee for Community-State Partnerships to Improve End-of-Life Care. She also played a very active role in the Initiative to Improve Palliative Care for African Americans, and she was responsible for securing funding for APPEAL: A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End. Her death was a loss to the community of those who work to improve end-of-life care for all Americans.

Disparities in Care

The United States is becoming increasingly diverse. Hispanic and Asian populations, in particular, are growing at much faster rates than the population as a whole, according to 2003 statistics released by the U.S. Census Bureau. Of the total U.S. population, Hispanics now constitute 13.7 percent, African Americans constitute 13.3 percent, and Asians 5 percent. Yet ethnic and racial minorities represent only 5 to 7 percent of patients in hospice, according to at least one study. Minorities are not receiving a proportional amount of hospice care, but as it turns out, this is just part of a larger trend.

According to the Institute of Medicine (IOM) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, racial and ethnic minorities tend to receive lower quality health care than whites do, even when they match insurance status, income, age, and severity of conditions. Minorities are less likely to receive routine medical procedures, are more likely to receive less desirable procedures (for example, limb

amputations for diabetes), and are less likely to receive life-prolonging treatments for HIV or cancer.

Factors Leading to Disparities

Research shows that a range of factors keeps diverse populations from receiving adequate medical care.

Unconscious Attitudes

According to the report, even medical providers who are consciously opposed to racist behavior may fall back on unconscious negative racial attitudes and stereotypes when diagnosing and treating patients, particularly given the time pressures and complexity of clinical settings.

Less Comprehensive Insurance

In addition, people with lower socioeconomic status are more likely to be enrolled in affordable health plans that impose a larger financial burden on the patient by offering fewer resources along with higher copayments or deductibles. Patients may not be able to afford these expenses.

Remote Treatment Sites

Even when they have the same level of insurance as whites, minorities are less likely to have access to primary care providers in their communities. Further, the move toward enrolling Medicaid patients in managed care, the IOM says, “may disrupt traditional community-based care and displace providers who are familiar with the language, culture, and values of ethnic minority communities.”

Lack of Cultural Sensitivity

Patients and health care providers may be from other cultures and thus may have very different understandings of death, of what and how to communicate, of the meaning of pain, of the limitations of medical science, of the responsibilities of family, of the right to self-determination, and of the state’s role in helping individuals.

History of Abuse

Minorities may mistrust medical providers because of a history of abuse and because care providers may make faulty assumptions and lack respect for cultural differences. For example, African American patients may suspect that the medical system doesn’t have their best interests in mind, and may therefore insist on ICU care and aggressive medical interventions at the end of life.

Continues on page 4



Photo: Susie Fitzhugh

Experts say that racial and ethnic minorities tend to receive lower quality health care than whites do, even when they match insurance status, income, age, and severity of conditions.

Disparities in Care*Continued from page 3***Language Barriers**

Programs have little capacity to adequately translate documents, educational materials, and conversations between providers, patients, and families. In California, for example, providers may work with patients who speak only or mostly one of more than 200 languages. This lack of capacity to communicate may result in nonexpert translators giving a skewed version of the message or in family members—even young children—being inappropriately recruited to communicate on behalf of the medical system.

All of these factors prevent access to care, forestall real conversations about preferences, keep patients from receiving adequate care at the end of life, and cause real emotional distress for patients and families.

New Policy Directions

Experts call for greater cultural competency and sensitivity about different cultures and acknowledgment of difference in policymaking. And they consistently point to the need for funding. Many programs struggle to provide adequate end-of-life care to

those who have access to medical services, feel comfortable receiving care, and have the resources needed to navigate the system. Programs tend to lack the resources that would allow them to overcome the many barriers that keep minorities from having adequate end-of-life care. So, while experts call for policy that would address these disparities, they also remind policymakers that implementation of such policy will require a significant and steady stream of financial resources from the states.

Policymakers who wish to address the barriers to adequate end-of-life care for minorities can mandate that care providers receive training in cultural competence, that hospitals have rooms large enough to accommodate families who wish to be involved in decision-making about a patient, and that hospices provide materials in the languages of those communities they serve. And, as the IOM report points out, the health care system at large needs more minority health care providers, especially since they are more likely to work in medically underserved communities.

**Abriendo Puertas:
A Model of Service for Hispanic Communities**

Hospice by the Sea (HBTS), in Boca Raton, Florida, is committed to providing staff with the training they need to provide culturally sensitive care to members of ethnic and racial groups that live in the region. They have developed Abriendo Puertas (Opening Doors), a model for culturally responsive end-of-life care for the Hispanic community. The program provides palliative care, bereavement counseling, and any other services families may need, such as organizing volunteers to bring food, helping families with long-distance and international communication, or even helping to send remains back to a home country. “Families are often fragmented, with some here and some in their home country,” says director Mari Chumaceiro. “Our program becomes a support system during a terrifying and lonely time. The families we work with are so grateful for our help.”

Abriendo Puertas uses a bilingual hospice team—nurses, physicians, social workers, volunteers, and spiritual counselors—to work with the patients and their families. It is important, Chumaceiro notes, that caregivers can speak English as well as Spanish: “While older members of the family may be comfortable in Spanish, the younger people may prefer English.



An Abriendo Puertas staff member with a patient who is receiving care at home through a program that provides culturally responsive end-of-life care to the Hispanic community. Abriendo Puertas uses a bilingual hospice team that includes nurses, physicians, social workers, volunteers, and spiritual counselors to meet the needs of patients and their families.

Unequal Access to Pain Treatment

The team needs to be able to support the patient and the family and needs to be able to communicate easily with everyone. All of our materials are in both Spanish and English, too." In Hispanic culture, discussing death is difficult, so the program offers support to Hispanic patients, families, and doctors, making it easier to broach the subject in a friendly and familiar atmosphere.

"Our program becomes a support system during a terrifying and lonely time. The families we work with are so grateful for our help."

Mari Chumaceiro, director,
Abriendo Puertas

HBTS is now starting a parallel program for African Americans, according to Neal Mize, a medical anthropologist who trains staff in cultural competence: "We are building on what we learned through Abriendo Puertas." The spiritual life of African Americans is often rooted in the church, though it is a church with different traditions and structures from those that are central to the Hispanic community. A program serving African Americans has to take into account beliefs in miracles, prayer, and reliance on God, says Mize. It also has to address families' suspicions that the medical system—including hospice—is indifferent or hostile to African Americans or that it will exploit them, he says. ■

For more information about the programs of Hospice by the Sea, visit www.hospicebytheseafl.org.

According to the Institute of Medicine (IOM) report *Unequal Treatment*, minorities confront discrimination when seeking pain treatment. Other research also shows that racial, sexual, and class discrimination are profound barriers to pain management.

The IOM reports that minorities get less treatment and lower quality treatment than whites and are less likely to receive "even routine medical procedures." A 2001 study found that male doctors prescribed twice the level of analgesic medication for white patients than for African Americans. Studies also suggest that poor people receive less pain treatment than the wealthy, that untreated pain levels are inversely proportional to income, and that women are less likely than men to be treated for pain.

Entire communities may not have access to necessary pain medication. For example, in a 2000 study of New York City's boroughs, only 25 percent of pharmacies located in mostly non-white neighborhoods were found to stock adequate supplies of opioid medications; in white neighborhoods, just under three-quarters did. "The disparity that we observed between white and non-white neighborhoods was very disturbing," says R. Sean Morrison, MD, Mount Sinai School of Medicine, the study's lead author.

Previous studies have observed that African Americans or Latinos with cancer are at increased risk for not being prescribed pain medications. These studies, taken together with the New York pharmacy study, suggest a vicious cycle for minority patients with pain, states Morrison. "Physicians do not prescribe these medications and as a result, pharmacies in minority neighborhoods do not experience a demand for them. When

patients are prescribed opioids, their local pharmacies often do not carry them. The result is unnecessary suffering."

Pharmacists told the researchers that just the threat of a DEA investigation was enough to prevent them from stocking Schedule II controlled substances. According to Susan Winckler of the American Pharmacists Association (APhA), in addition to worrying about the DEA, "there is a cost to having those medicines on the shelf. There is a cost to all that record-keeping." Add to that the problem of poor patients on Medicaid, which pays a low rate and takes weeks or months to pay: "If patients can't pay the pharmacist for the medications on the shelf, there are limits on what the pharmacist can do to help them," Winckler says.

Winckler explains that the APhA works with pharmacists to teach them ways to meet the expectations of the DEA. They also help DEA agents understand that "just because the pharmacy is the highest dispenser of Schedule II narcotics in the county, that's not necessarily a sign that there's diversion."

A 2001 study found that male doctors prescribed twice the level of analgesic medication for white patients than for African Americans.

The Barriers of Poverty and Rural Isolation

For Americans of any race or ethnicity, life circumstances—such as poverty or rural isolation—can put people outside mainstream culture and medical care.

Living and Dying in Poverty

According to the U.S. Census Bureau, in 2003 the number of Americans without health insurance grew to 16 percent (up from 14.2 percent in 2000). In addition, the number of Americans living in poverty increased to 12.5 percent (from 12.1 percent in 2002). Single-parent families were especially hard hit, with the poverty rate among households headed by a single woman reaching 28 percent, from 26.5 percent in 2002.

People with low incomes who are dying are subject to additional pressures that increase their suffering and keep them from getting adequate end-of-life care, according to Beverly Williams, PhD, University of Alabama at Birmingham Center for Aging. The demands of a poverty lifestyle may exclude low-income people from diagnosis and treatment and keep them from attending to their condition. They may see themselves as having no time to have surgery or be in the hospital. They may see themselves

as having no money for treatment and no options. “This is the other America,” Williams says. “They work long hours for low pay. They have no sick leave or insurance. They can’t leave the job to see a doctor or they will lose pay or even the job.”

Because of the stresses of living in poverty, diseases that affluent people typically experience late in life occur at midlife for the poor, Williams says, citing research. And since American culture tends to promote the idea that terminal illness is avoidable if people take good care of themselves, low-income people are often blamed (even by themselves) for becoming ill. Distressingly, the implications of serious illness and death have not only an emotional impact but often a devastating economic impact as well on the patient’s family. If a family lacks health or life insurance, a death can leave a family bereaved, without a source of income, and with huge expenses.

A Program That Helps Patients Qualify for Hospice Care

The Balm of Gilead in Birmingham tries to address the needs of people who do not qualify for hospice care, typically because they lack homes or caregivers. While most of the patients they help are African American and urban, they also assist white and rural patients. The Balm works with patients to find a living situation, get them into hospice care, and help them manage pain and other symptoms. The program is currently moving from grant-based funding to hospital-based funding, a shift that has forced them to set aside some innovative practices, which points, again, to the need for consistent funding for programs that help underserved populations. The Balm was recently profiled in the *Journal of Palliative Medicine* (vol. 7, no. 3, 2004).

Getting Care in Pioneer Rural Areas

In some states, there are counties that have only one or two thousand people spread out across a large area, called a “pioneer rural” area. Culturally, people living in pioneer rural areas tend to be strongly independent and dedicated to sustaining themselves. They may find it difficult to rely on people outside their immediate families, and with the increasing mobility of American life, their families may no longer live in the area. In addition, it is difficult for anyone who is sick to travel long distances for care.

Travel time for hospice workers is a big issue, since workers may only be able to see two patients in a day. Population-based formulas for calculating reimbursement don’t work for hospices in these areas. In very rural areas, a lone hospital gets a sole provider rate of reimbursement that covers actual costs of providing service. This means that rural people have access to acute care, but not necessarily hospice. Some experts have been arguing for sole provider status for hospices that access benefits administered through Medicare. This would mean that hospices would be reimbursed for the actual costs of providing care to patients living in extremely rural settings (including extensive travel time, for example), rather than being paid a per diem that is based on the costs of providing care in an urban environment.

According to Donna Bales, president and CEO of the LIFE Project, “Policymakers should understand that better end-of-life care will not be available to people in frontier rural areas until there is funding to pay for it.” ■

“Policymakers should understand that better end-of-life care will not be available to people in frontier rural areas until there is funding to pay for it.”

Donna Bales, president and CEO,
LIFE Project

Barriers for People with Disabilities

According to Census 2000, nearly one in five Americans over the age of five has at least one disability. Some disabilities leave a person incapable of informed judgment, while other disabilities affect only the body, not the individual's mind, will, or desire to live and die well. According to disability rights advocates, when individuals with disabilities are dying, they should have their pain and other symptoms managed, they and their families should be supported spiritually and socially, and their preferences and needs should be respected and fulfilled.

Hugh Gregory Gallagher, who died recently, was a dynamic force in the area of disability rights. According to Gallagher, "people in the mainstream disabilities community tend to be in denial about death because they have been so beaten up by the medical profession and by their own original trauma." American culture tends to devalue the lives of people with disabilities; the able-bodied (including health care providers) may refuse to acknowledge that people can live meaningful lives with chronic conditions and disabilities. People with disabilities cannot trust caregivers when they feel that they are seen as inconvenient or expendable, according to Gallagher and others.

Experts report that it is difficult to find health care facilities that can treat the acute health problems of people with disabilities while helping them manage their daily lives. This may result in people with disabilities going to hospitals with minor conditions and leaving with skin ulcers that can last for months, according to Lex Frieden, professor of physical medicine and rehabilitation at Baylor College of Medicine. Palliative care programs often excel at keeping people with disabilities comfortable.

Those who are disabled wards of the state face even more barriers to effective care when they are dying. Gary Stein, executive director, New Jersey Health Decisions, says that state policies can create barriers to getting palliative care for someone with a state guardian. New Jersey Health Decisions developed the Disability Ethics Network (DEN) using the model of hospital ethics committees to help people with disabilities (especially those in state-run developmental centers and community group facilities). DEN assembles an interdisciplinary team (social workers, physicians, nurses, advocates, and others) to analyze the medical, ethical, and legal issues relating to health care decisions for individual patients who are without decisionmaking capacity. The patient, caregivers, and guardians are heard and respected during the process.

DEN also offers training to social workers, medical care providers, and workers in the State Bureau of Guardianship Services. DEN has worked with the state to develop regulations that will provide for hospice and palliative care for people under guardianship who are expected to live less than a year.

The regulations are published in the New Jersey Administrative Code 10:48B. They took time and research to develop, notes Kim Friend, chief of the Bureau of Guardianship Services: "The process of learning what the community needed was good for us. It's worth the time it takes to develop a living, breathing policy that really meets individuals' needs. Because of this careful work, people are able to die with comfort and dignity."

Policy Goals

for People with Disabilities

Experts argue that improved policy can support the rights of people with disabilities and ensure that they get adequate end-of-life care.

Protect Rights

Observe and protect the rights and choices of people with disabilities and ensure that their lives are valued by the medical and legal communities and by the staff of public agencies.

Mandate and Help Fund Training

Ensure that training for physicians, other medical providers, and agency staff will prepare them to work effectively with people who are disabled and help them manage tasks of daily living. Facilities, equipment, and procedures may need to be adapted in order to accommodate patients.

Revise Reimbursement Policies

Revise Medicare reimbursement guidelines to allow doctors enough time to communicate with patients with disabilities and their families. Doctors need to know about patients' pain and other symptoms, their preferences, and their social contexts. This takes time that is too often not available because doctors are not adequately reimbursed for it.

Ensure Adequate Pain Management

Palliative care to control pain and other symptoms can help people with disabilities long before death, but policies restrict payment for hospice care to patients expected to die within six months, keeping patients with disabilities out of services that could improve their quality of life. Palliative care should be available to patients with disabilities sooner.

Tailor Policy to Support Real Needs

Determine policy governing the care of state wards by the needs of the individuals, not their status as wards. State policies can support effective end-of-life care for those who are wards of the state, including regulations for advanced directives where appropriate.

Issues 12 and 13 of *State Initiatives in End-of-Life Care* provide detailed information on disability and guardianship issues.

End-of-Life Issues and the Gay Community

Gay people die of everything that kills heterosexuals, too: they die of heart disease, cancer, strokes, and any number of other diseases, traumas, or conditions. The gay community has developed some excellent end-of-life care programs for people with AIDS, but a gay person who is dying of some other disease or condition is likely not to find end-of-life care that supports his or her identity. In addition, say experts, as drug therapy for HIV has improved, even AIDS programs have de-emphasized their focus on end-of-life care.

Many gay people feel that they will not have anyone to take care of them if they need help. In fact, according to Reverend Ken South, Rainbow Aging Consultants, studies show that 80 percent of all care for frail elderly people is done by family, but 80 percent of gay people don't have family: they don't have children and may be estranged from their families of origin. So while gay siblings may be expected by other family members to take care of elderly parents because they don't have children, it is unclear who will take care of the gay siblings when they are elderly or dying. South explores these and other issues in the report *Outing Age*, available from the National Gay and Lesbian Task Force (visit www.thetaskforce.org/reslibrary/list.cfm?pubTypeID=2 and click on the *Outing Age* download icon).

Because same-sex partnerships are less likely to be recognized by states, gay and lesbian couples often cannot access benefits automatically available to heterosexual married couples, including leave from work to care for an ill or dying partner, survivor benefits from private insurance or pensions, or income and asset protection for the partner of a nursing home resi-

dent. These differences create significant hardships at the end of life for gay and lesbian people.

While gay couples may plan for care at the end of life, their preferences and their partners may be ignored by family and the medical establishment. "Next of kin is a very powerful legal precedent," Ken South says. A few states, like West Virginia, have health care decision laws that embrace non-blood or marriage relations.

Some gay people may refuse home health care because they are afraid that the home health workers will harm them or treat them disrespectfully when they find out about their sexual orientation. In particular, older gay people may not feel comfortable coming out to their health care providers, making them feel like they are living inauthentically in their last days. A 1994 study by the Gay and Lesbian Medical Association found that 52 percent of gay doctors in the study saw colleagues deny or reduce care to patients based on their sexual orientation. Health care providers need training that will allow them to create an environment that supports all their patients.

"If you look at the continuum of care for someone who is gay, from diagnosis to death, at almost every moment, gay and lesbian issues have a presence, whether it has to do with health insurance, interactions with doctors and other providers, treatment, home care, hospice, relationships with family, final decisions, death, burial, or bereavement," says South. ■

► New Policy Brief Series Addresses the Nursing Shortage

State Initiatives in End-of-Life Care

Information about the Series

"Diversity and Discrimination: Policies to Address Disparities in End-of-Life Care" is the 24th in a series of briefs profiling promising policies and practices in end-of-life care.

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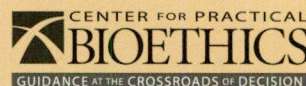
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Editorial guidance for the *State Initiatives* series is provided jointly by the Center for Practical Bioethics (CPB) and The Robert Wood Johnson Foundation. The Foundation supplies series funding.

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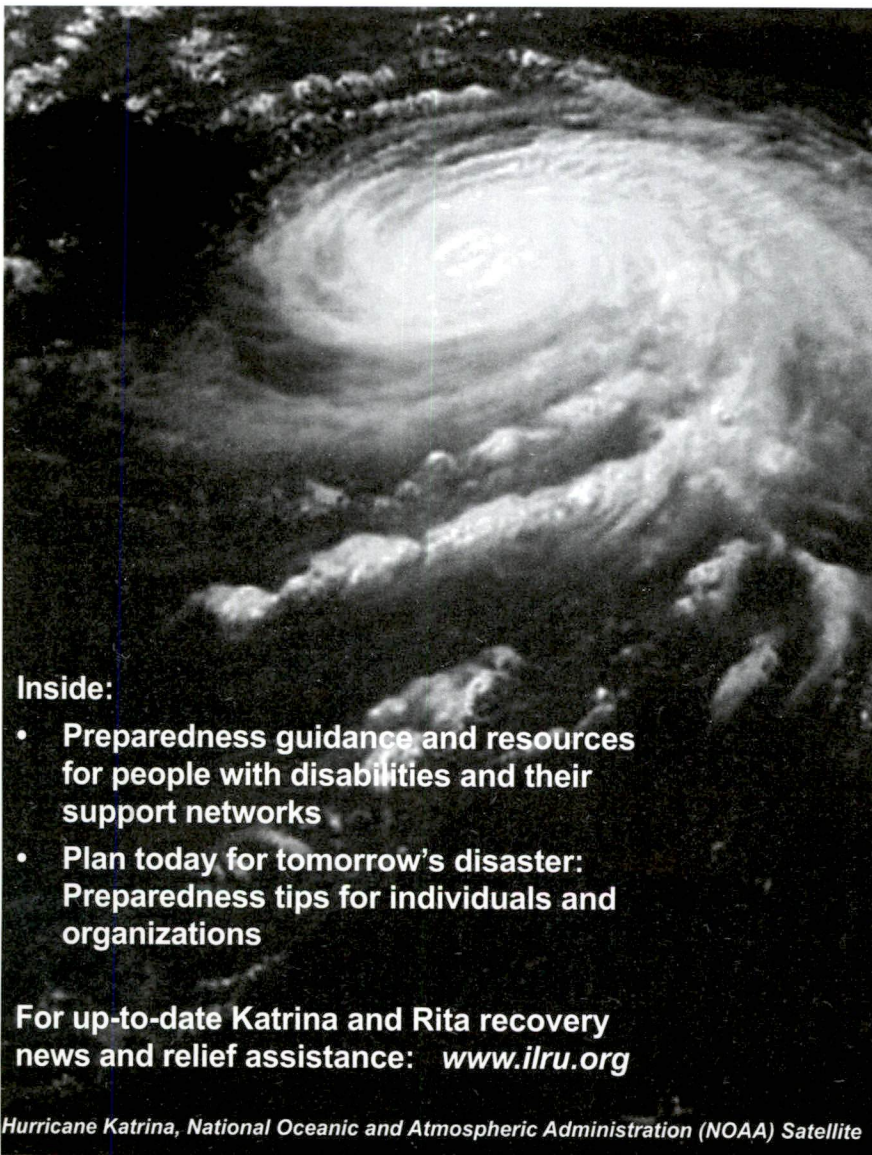
ilruNetWork

Published by the IL Net, a collaboration of ILRU and NCIL

October 2005

How well are YOU prepared for a hurricane, flood, fire, terrorist attack or other

EMERGENCY!



Inside:

- Preparedness guidance and resources for people with disabilities and their support networks
- Plan today for tomorrow's disaster: Preparedness tips for individuals and organizations

For up-to-date Katrina and Rita recovery news and relief assistance: www.ilru.org

Hurricane Katrina, National Oceanic and Atmospheric Administration (NOAA) Satellite

As I write, the states along the Gulf Coast are recovering from Rita—a category three hurricane. This time, the east Texas and West Louisiana coasts were the targets. Here in Houston, ILRU's headquarters, thousands of Katrina evacuees who remained in shelters were evacuated to another state. And many of those of us who live here and in the surrounding areas evacuated, too.

It all serves to reinforce the message we hope to convey with this newsletter—disasters happen. They don't ask for permission. They don't wait until we're ready. The responsibility for preparedness rests on us.

Katrina served up a powerful reminder that many first-responders and relief agencies still don't grasp the obstacles that confound people with disabilities and other vulnerable citizens in times of crisis. The independent living community can and should be a major player in changing that.

In the months to come, the ILNet is committed to advancing that idea. We will have plenty of things to talk about and work through, thanks to our experiences and lessons learned in this catastrophic hurricane season.

First, though, we need to make sure that IL consumers, staff and centers have their own "preparedness acts" together. For some in our community, it is truly a matter of life and death. For that reason, those of us in the business of serving and supporting people with disabilities have a particular responsibility to be sure we are prepared and able to respond when and where disaster strikes.

—Richard Petty, ILNet Director

“For people with disabilities the disaster has not ended. The press and others might have you believe we’re through the rescue phase of the crisis. In fact, many people with disabilities are still in need of a certain type of rescue—and they will be for some time.” —Lex Frieden

Frieden shares lessons learned in 2001 Houston flood

People that know him—people around the world—know that Lex Frieden wears a lot of different hats as an advocate for people with disabilities. He is the chairperson of the National Council on Disability, a professor at Baylor College of Medicine, a senior vice president at TIRR (The Institute for Rehabilitation and Research) and director of ILRU. And that’s the short list.

The experience that best prepared Frieden for a leadership role in the national response to people with disabilities devastated by Hurricane Katrina, however, has less to do with any of those and much more to do with personal experience. Frieden and his family are survivors of another weather disaster—Tropical Storm Allison—which sent destructive flooding through downtown Houston in 2001. They had an “up close and personal” confrontation with the overwhelming fear, uncertainty, confusion, frustration and loss that millions of people in the Gulf Coast states are experiencing now.

Frieden—a quadriplegic as the result of a spinal cord injury—understands the (literally) sinking feeling of being reliant on a wheelchair that is being swallowed by rising water. His family will never forget the agonizing wait to be evacuated, the sad realization their home was uninhabitable or the seemingly endless paperwork and red tape associated with getting help from disaster relief agencies.

Frieden recalled what he learned from that experience in a recent nationwide webcast sponsored by ILRU. He was joined by Mark Johnson, advocacy director at Atlanta’s Shepherd Center, and Richard Petty, ILNet director. Among other topics, the wide-ranging discussion included advice for individuals and families who need assistance to recover from the catastrophe, ideas for CILs and others for ways to assist people with disabilities in this time of crisis, and the need to document the ongoing barriers and problems people with disabilities have experienced as they try to recover from the disaster and move on with their lives.

(Note: Highlights on specific webcast topics appears as boxed information throughout this newsletter. —Ed.)



Lex Frieden, 2001 Houston flood survivor

ADVICE TO SURVIVORS

Be persistent, be clear, be strong

- **Get registered with FEMA.** Register online (if you have computer access) or call as often as you need to get through. Don’t give up. Being registered is critical for receiving the array of FEMA’s relief services that will be available in the near future.
- **Be absolutely clear in your communications with FEMA and other relief agencies that you are a person with a disability who has special needs.** Be very clear about what your needs are. They cannot be expected to address needs or resolve issues they don’t know about.
- **Temporarily, a number of organizations are offering housing; but, eventually, FEMA will be the main housing provider.** The agency has an elaborate system to determine need and how much money they will provide people. Be sure to indicate the extent of your need for accessible housing. They can waive some policies—if they are aware of your need.
- **When FEMA asks you to list family members you should only list persons in your immediate family unit.** Do not include members of your extended family or other persons who do not ordinarily live with you. Doing so could affect how much money you get. They should register separately.
- **Link up with a center for independent living or some other organization or person who can work as your advocate or case manager.** They can make calls on your behalf and generally help you navigate the complicated maze relief agencies and supports.
- **Keep a notebook, an envelope or some other way to keep up with the various papers, numbers, cards, etc. you will collect in your dealings with relief organizations and others.** It’s important to keep them with you.
- **Typically, once you get past the intake desk at a FEMA center, people staffing the various desks (financial assistance, housing, etc.) will be knowledgeable about specific relief benefits.** There should also be at least one person who understands disability-related issues. If at any time you feel the people you are talking to are not responding to your particular disability-related needs, ask to speak to a supervisor who is more likely to be knowledgeable.

FEMA CONTACT INFO:

800-621-FEMA (3362)

800-462-7585 (TTY)

<http://www.fema.gov>



A few things to know, do and have before registering with FEMA

(Source: www.fema.gov)

- ☐ Katrina and Rita survivors who want federal disaster recovery assistance *must* register with the Federal Emergency Management Administration (FEMA).
- ☐ Applicants can register by telephone or online. (Note from FEMA's website: "Currently, to complete your application online you must be using Microsoft's Internet Explorer 6.0 or above. We are in the process of modifying the application so that it will be available to additional browsers.")
- ☐ FEMA *will not* accept applications by mail.
- ☐ At the end of the registration process (either phone or online) applicants will be given a identification number. It's important to write the number down and keep it handy—it is how a claim will be identified throughout the recovery process.
- ☐ Have pen and paper available to record information during the registration process.
- ☐ Whether registering by phone or electronically, applicants will be asked to provide the following:
 - Social Security Number (individuals) or tax ID number (businesses): If you do not have a social security number, your household may still be able to receive assistance if there is a minor child in the household who is a U.S. Citizen, Non-Citizen National, or Qualified Alien with a social security number.
 - Insurance information: You will be asked to identify the type(s) of insurance coverage you have.
 - Financial information: You will be asked to enter your family's gross total household income at the time of the disaster.
 - Contact information: Along with the address and phone number where the damages occurred, you will be asked for information on how FEMA can contact you. It is very important that you provide FEMA with your current mailing address and phone numbers where you can be contacted.
 - Electronic Funds Transfer (EFT)/Direct Deposit Information (optional)
 - If you are determined to be eligible for assistance and would prefer that funds be transferred to your account, you will be asked for your banking information, which includes the institution name, type of account, routing and account number.

Who did Katrina leave behind?

Houston survey gives first glimpse of survivors' issues

More than one in 10 (14%) Hurricane Katrina evacuees report a family member, neighbor or friend was killed by the storm or subsequent flooding and more than half report that their home was destroyed (55%) and that they are separated from or missing members of their immediate family (53%). The survey also found that evacuees in Houston shelters face serious health challenges that will complicate relief and recovery efforts.

Key health-related findings include:

- 52% report having no health insurance coverage at the time of the hurricane. Of those with coverage, 34% say it is through Medicaid and 16% through Medicare.
- Before the hurricane 66% of the people evacuated to Houston shelters used hospitals or clinics as their main source of care and of those, a majority (54%) used Charity Hospital of New Orleans,

substantially more than the second most common care site (University Hospital of New Orleans, at 8%).

- 33% report experiencing health problems or injuries as a result of the hurricane and 78% of them are currently receiving care for their ailments.
- 41% report chronic health conditions such as heart disease, hypertension, diabetes and asthma.
- 43% say they are supposed to be taking prescription medications, and of those, 29% percent report having problems getting the prescription drugs they need.
- Of the 61% who did not evacuate before the storm, 38% said they were either physically unable to leave or had to care for someone who was physically unable to leave.

Among those surveyed, 98% are from the New Orleans area and about three-quarters of those (73%) have lived there their whole lives. In surviving this tragedy, an overwhelming majority of the evacuees in Houston shelters (92%) say that religion played an important role in helping them get through the past two weeks.

SOURCE: Survey of evacuees in shelters in Houston sponsored by *The Washington Post*, Kaiser Family Foundation and Harvard School of Public Health. Find detailed information online: <http://www.kff.org>.



Lessons learned from 9-11 still apply as CILs re-evaluate disaster plans after Katrina

No two disasters are exactly alike, so there's probably no way to plan for everything that will happen during or after an emergency. Still, we can learn from folks who have actually been through the experience. With that in mind, we offer the following tips—listed in no particular order—garnered from interviews with Center for Independence of the Disabled, New York and the New York Statewide Independent Living Council in reflecting on their own preparedness in the aftermath of Sept. 11, 2001. Based on what we are learning about the Katrina aftermath (from consumers and service providers), the information still seems relevant. —Ed

- The best preparedness plans include a “Plan B”—just in case the situation makes “Plan A” impossible. For example, a plan that relies on telephoning consumers to check on their safety will be useless if phone lines aren’t working or are overloaded.
- Even if transportation systems are not damaged, emergency response personnel may restrict travel for security or other reasons. For example, personal vehicles were not allowed into Manhattan for a period of time after the attacks. Without public or special transit, people who had medical appointments or needed to travel to apply for relief benefits or other important business had no way to get into town.
- If emergency shelters and temporary housing are not accessible, they’re of no use to many people with disabilities. It’s not enough to plan to evacuate folks—they’ve got to be able to get in and around emergency lodging.
- When closed captioning and TDDs go down, many people who are deaf have no access to critical information about evacuation, emergency shelter, medical services, relief assistance, etc. Restoring and maintaining communications to this population should be a priority in any emergency response plan.
- People who provide services to consumers may be impacted by the crisis, too. For example, a personal assistant may be injured, stranded, cut off from communication or otherwise affected by the disaster—just like everybody else. Emergency response plans need to take this into account and provide for some type of backup arrangements.
- Don’t assume that emergency and relief agencies understand accessibility, accommodations, communication, transportation issues or any other aspect of disability or independent living. If you haven’t worked to raise their awareness before the emergency, plan to spend a lot of time educating them in the midst of the crisis.
- If you’re near the state line, your emergency response may need to include two states. Learn in advance what needs to happen to account for differences in services and systems.
- The news media is a valuable resource in reaching out to constituents in a time of crisis. Include a media plan in your overall emergency response plan.

Good (and free!) preparedness resource for CILs and others

What if your CIL sits right in the path of the next disaster. Maybe it’s a hurricane. Perhaps a flood. Possibly a fire.

How will you communicate with staff and consumers to make them aware of the problem or check on their well-being? How will you access important records and documents if you can’t get back to your office? What if your records are destroyed in the disaster? How will you assure that consumers who rely on you for services and supports are getting what they need? How quickly will you be able to restore your operations—with or without your office?

Being truly prepared for a disaster is something most of us say we’ll get around to—some day. Unfortunately, catastrophe doesn’t abide by our schedules. For CILs, not being prepared when disaster strikes could have serious—possibly life-threatening—consequences for people with disabilities.

In searching for good resources to help CILs assess and enhance emergency readiness, ILNet came across the Public

Entity Risk Institute (PERI). PERI’s website (www.riskinstitute.org) is loaded with excellent information on risk management, disaster preparedness and related topics.

One publication in particular caught our attention. *Open for BusinessSM* is a free comprehensive disaster planning toolkit that includes great tips, checklists and forms that help organizations evaluate and plan for emergencies.

The booklet was developed by the Institute for Business and Home Safety (IBHS), with PERI funds. You can download it at www.ibhs.org/docs/OpenForBusiness.pdf. Like PERI, IBHS (www.ibhs.org) has a lot of useful information you may want to check out while you’re there.

The following paragraphs are excerpted from the 47-page guide as a sampling of the tips available for two communications methods CILs regularly depend on—computers and telephones.

Computer Considerations

“When there is sufficient warning about an event, such as a hurricane, you might decide to move some of your computer equipment and software to a safe place, so that it could be utilized at your recovery location. ... In addition, you could require that all employees take their laptops with them, in order to provide the option to work from home or at a recovery location.

“Some disasters occur without warning, though, so you want to be sure you have alternatives available. Other reminders:

- Keep a backup copy of your computer’s basic operating system, boot files, and critical software, and be sure you have copies of your operations manuals.
- Maintain an up-to-date copy of computer and Internet logon codes and passwords.
- Make arrangements with computer vendors to quickly replace damaged vital hardware and software, and/or to meet your needs at your recovery location.

See **COMPUTER** on page 6

Advice to relief workers: Take care of yourselves!

The following is an excerpt from the Sept. 10 entry in the online "ILRU Disaster Relief Journal" available on ILRU's home page: www.ilru.org.

It will be many months—possibly years—before we can really feel that all the problems are resolved for the survivors of the recent hurricanes. Those of you on the front lines of assistance are so important to the effort. We include this information hoping you will pay attention to your own physical and mental health. —Ed.

CIL staff have been on the front lines of disaster recovery for several weeks now. The same is true for SILC staff and so many other organizations that serve people with disabilities. As in the 911 attack and other disasters, the IL community has responded with lightening-quick aid to the people in need. It is crucial to make sure you're taking care of yourselves, even as you assist and support others. We wanted to offer some self-care tips, as well as resources to help you help others.

You've been called on to do the almost impossible in the midst of chaos and without telephones, electricity, or running water. For some of you, your own homes have been destroyed and families scattered. Yet, you've continued to work to find those who are missing, helped secure shelter, food, water, medical supplies and equipment, and now, you're helping to locate more permanent housing. You have been true heroes. Our hearts go out to you and you are constantly in our thoughts and our prayers.

Most of you've have had little sleep—and almost certainly, no good rest. Many of you have told us of your exhaustion and of your great frustration and anger with systems that seem to have completely ignored people with disabilities. It is crucial to make sure you're taking care of yourselves, even as you assist and support others. We wanted to offer some self-care tips, as well as resources to help you help others.

The staff of SAMHSA, a federal agency that deals with mental health issues, have prepared *Self-Care Tips for Emergency and Disaster Response Workers*. The SAMHSA publication emphasizes that no one responding to a disaster is untouched by it. The is one of a number of publications related to disaster/trauma available on the agency's website: www.mentalhealth.samhsa.gov.

Self-Care Tips for Emergency and Disaster Response Workers

Normal Reactions to a Disaster Event

- ☐ No one who responds to a mass casualty event is untouched by it
- ☐ Profound sadness, grief, and anger are normal reactions to an abnormal event
- ☐ You may not want to leave the scene until the work is finished
- ☐ You will likely try to override stress and fatigue with dedication and commitment
- ☐ You may deny the need for rest and recovery time

Signs That You May Need Stress Management Assistance

- ☐ Difficulty communicating thoughts
- ☐ Difficulty remembering instructions
- ☐ Difficulty maintaining balance
- ☐ Uncharacteristically argumentative
- ☐ Difficulty making decisions
- ☐ Limited attention span
- ☐ Unnecessary risk-taking
- ☐ Tremors/headaches/nausea
- ☐ Tunnel vision/muffled hearing
- ☐ Colds or flu-like symptoms.
- ☐ Disorientation or confusion
- ☐ Difficulty concentrating
- ☐ Loss of objectivity
- ☐ Easily frustrated
- ☐ Unable to engage in problem-solving
- ☐ Unable to let down when off duty
- ☐ Refusal to follow orders
- ☐ Refusal to leave the scene
- ☐ Increased use of drugs/alcohol
- ☐ Unusual clumsiness

"The more we acknowledge and deal with our own feelings, the better we will be able to support and help our staff and colleagues—and the better we all will be able to support and help the people in our communities."

—2001 ILRU NetWork

Ways to Help Manage Your Stress

- ☐ Limit on-duty work hours to no more than 12 hours per day
- ☐ Make work rotations from high stress to lower stress functions
- ☐ Make work rotations from the scene to routine assignments, as practicable
- ☐ Use counseling assistance programs available through your agency
- ☐ Drink plenty of water and eat healthy snacks like fresh fruit and whole grain breads and other energy foods at the scene
- ☐ Take frequent, brief breaks from the scene as practicable
- ☐ Talk about your emotions to process have seen and done
- ☐ Stay in touch with your family and friends
- ☐ Participate in memorials, rituals, and use of symbols as a way to express feelings
- ☐ Pair up with a responder so that you may monitor one another's stress

Source: www.mentalhealth.samhsa.gov

Personal Preparedness

(You have to start preparedness planning somewhere. We offer these quick checklists to help CIL staff and consumers launch their own readiness preparations. —Ed.)

Checklist: Things to have, know and do

- Establish a *personal support network*.
- Customize an *emergency health information card* (see sample on p. 8). Keep copies in wallet, purse and emergency supply kits.
- Complete an *emergency contact list*.
- Collect *emergency documents*.
- Store *emergency documents* in emergency supply kits, wallet, safe deposit box and give copies to personal support network and out of area contact.
- Conduct an *ability self-assessment*.
- Collect “*carry-with-you*” supplies to keep with you at all times.
- Collect *disability-related supplies* for emergency kits.
- Maintain a seven-day supply of *essential medications*.
- Keep *important equipment and assistive devices* in consistent, convenient and secured place.
- Write out *instructions for things you will need help with* in an emergency.
- *If you use a service animal see the checklist on page 7.*

Support networks: Important things to remember

- Make arrangements, prior to an emergency, for your support network to immediately check on you after a quake and, if needed, offer assistance.
- Exchange important keys.
- Show where you keep emergency supplies.
- Share copies of your relevant emergency documents, evacuation plans and emergency health information card.
- Agree on and practice a communications system regarding how to contact each other in an emergency. Do not count on the telephones working.
- You and your personal support network should always notify each other when you are going out of town and when you will return.
- The relationship should be mutual. Learn about each other's needs and how to help each other in an emergency.

Checklist: Things to keep with your or have handy in a crisis

- Emergency Health Information Card
- Instructions on personal assistance needs and how best to provide them
- Copy of emergency documents
- Essential medications/copies of prescriptions (at least a week's supply)
- Flashlight on key ring
- Signaling device (whistle, beeper, bell, screecher)
- Small battery-operated radio and extra batteries
- Disability-related supplies to add to regular emergency kits*

**You won't carry your extra disability-related supplies with you all the time—but do keep them where you can get to them easily. Plan for enough supplies for up to two weeks (medication syringes, colostomy, respiratory, catheter, padding, distilled water, etc.). Don't expect shelters or first aid stations to meet your supply needs.*

SOURCE: www.preparesnow.org

COMPUTER continued from page 4

- Request written estimates for rental or purchase, shipping costs and delivery times, if relevant. Be sure to list these companies in your suppliers/vendors form as either primary or alternate vendors.
- Elevate computer equipment normally stored on the floor, e.g. CPU's, and secure in place when flooding is a possibility. Remember that you should always keep your computer hardware and software licenses up to date.”

Telephone Tactics

“... Communication with employees, vendors, customers, emergency officials and other key contacts is vital to your ability to resume business operations following a disaster event.

- Designate one remote voice mail number on which you can record messages for employees
- Arrange for programmable call forwarding for your main business line – if you cannot physically access your business, you can call in and reprogram the phones to ring elsewhere. (Keep in mind that if telecommunications engineers are swamped with requests to redirect phones, faxes and data lines to backup locations, your recovery location could be affected.)
- Consider alternative forms of communication should phones not be working, especially to keep in touch with your employees. In anticipation of a break in all phone service, including cell phones, you might invest in some simple two-way radios and pagers that just send signals to each other.
- Communicate by e-mail, postings on your website, or an emergency messaging system. As you think about your voice communication needs at your recovery location, determine whether you need speakerphones, voice mail capacity or the ability to record conversations. Also, decide if you need a conference bridge, in order to have conference calls with employees, key contacts, and/or customers to assess disaster damage and to make recovery decisions.
- ‘Plain Old Telephone Service’ (POTS), where the handset is connected to the base, will likely work during a power failure. The connection is direct to the telephone company, which has extensive back-up power.
- Cordless phones rely on electricity on site and may be useless.
- Cell phones may work if cell towers are still functional, but often system overload causes lost connections.”
(Source: www.ibhs.org)

Preparedness group lists "most important things" in disasters

Some disasters—like hurricanes—usually announce themselves, giving folks a little bit of time to collect necessities and evacuate, if needed. Other catastrophes—like earthquakes, tornados, explosions or fires—arrive without warning. People may be forced to stay in place for several days.

No group is more aware of that than the San Francisco Bay Area Emergency Preparedness Coalition. The organization—operating in the heart of earthquake country—works to "ensure that the needs and concerns of vulnerable people are addressed in emergency preparedness and response."

The following guidance from the organization appeared in the January 2002 ILRU Network. And it's still good advice. The Coalition has a number of good tip sheets and other information on its website: www.preparenow.org. —Ed.)

In the event of a serious disaster everyone should be self-sufficient for at least three days without help or emergency services, with streets closed and with no stores open. There may be no electricity, gas, water or telephone service. Remember your home is the best place to stay—if it is not too badly damaged to be safe. The most important things to have:

- ☐ Bottled water (3 gallons per person in small, easy-open bottles)
- ☐ Several flashlights (by the bed and around the house)
- ☐ One week supply of medicines (rotated regularly) and instructions for use—dosage, frequency, doctor's name and phone; post this information on your refrigerator under the heading EMERGENCY INSTRUCTIONS.
- ☐ First aid kit
- ☐ Shoes under the bed (to protect feet from broken glass—windows, lamps, etc.)
- ☐ Fire extinguisher (know how to use it)
- ☐ Smoke alarm (check batteries yearly)
- ☐ Battery operated radio or TV
- ☐ Whistle or loud bell (to attract attention)
- ☐ Wrench for gas turn-off (only if you or someone else smells gas)
- ☐ Garbage bags (for personal waste)

Emergency Health Information + Emergency Health Information +

Name _____

Street Address _____ City/State/ _____

Phone: Home _____ Work _____ Fax _____

Birth Date ____ / ____ / ____ Blood Type _____
Day Month Year

Social Security Number _____

Health Insurance Carrier _____

Individual Number _____ Group Number _____

Physician(s) Name _____ Physician(s) Phone _____

Emergency Contact(s) Name _____ Contact(s) Phone _____

Conditions/Disability _____

Medications _____

Assistance Needed _____

Allergies _____

Immunization Dates _____

Communication/Equipment/Other Needs _____

Emergency Health Information + Emergency Health Information + Emergency Health Information + Emergency Health Information + Emergency Health Information +

An emergency health information card communicates to rescuers what they need to know about you if they find you unconscious or incoherent—or if they need to quickly help evacuate you. Make multiple copies of this card to keep in emergency supply kits, emergency carry-with-you kits, car, work, wallet and purse (behind drivers license or primary identification card) wheelchair pack, etc. The form above can be folded down to wallet size.

HUMANE SOCIETY'S DISASTER PREPAREDNESS CHECKLIST FOR SERVICE ANIMALS AND PETS

- ☐ Medications and medical records stored in a waterproof container and a first aid kit. A pet first aid book is also good to include.
 - ☐ Sturdy leashes, harnesses, and carriers to transport pets safely and to ensure that your pets can't escape. Carriers should be large enough for the animal to stand comfortably, turn around, and lie down.
 - ☐ Current photos and descriptions of your pets to help others identify them in case you and your pets become separated and to prove that they are yours.
 - ☐ Food and water for at least three days for each pet, bowls, cat litter and litter box and a manual can opener.
 - ☐ Information on feeding schedules, medical conditions, behavior problems, and the name and number of your veterinarian in case you have to board your pets or place them in foster care.
 - ☐ Pet beds and toys, if you can easily take them, to reduce stress.
- (Source: www.hsus.org)



NetNotes

Some of the emergency preparedness information included in this newsletter came directly out of a newsletter we published in January 2002 following the 9-11 terrorist attacks. There was a lot of good information in that newsletter (*9-11 offers important lessons in disaster preparedness, IL NET, January 2002*), which is still available under the Publications/Newsletters links on the ILRU website: www.ilru.org.

The Center for Disease Control also has publications that may help you as you work with consumers displaced or affected by the disaster. Check out *Coping With a Traumatic Event* on the CDC website. There's a version for targeted to health care professionals and another for the public at www.bt.cdc.gov/masstrauma/copingpub.asp.

The National Center for Post Traumatic Stress Disorder has published www.ncptsd.va.gov/pfa/PFA.html

SAMHSA's National Mental Health Information Center has a number of online disaster/trauma publications targeted to a variety of segments of the population. To see the list, go to www.mentalhealth.samhsa.gov/cmhs/katrina/pubs.asp.

Since the beginning of this year, two federal organizations have published reports that included recommendations for emergency planning for people with disabilities. It seems clear these publications will be central to future discussions about how to do a better job of meeting the needs of people with disabilities in preparing for and responding to crisis situations.

Last April, the **National Council on Disability** published *Saving Lives: Including People with Disabilities in Emergency Planning*. As described on the NCD website, the report "provides an overview of steps the federal

government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security programs." Find an electronic copy of the report at www.ncd.gov/newsroom/publications/2005/saving_lives.htm.

In July, the **Federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities** published its own recommendations to President Bush in its first annual report. It's available online at www.dhs.gov/interweb/assetlibrary/CRCL_IWDEP_AnnualReport_2005.txt. The ICC was established to ensure that the Federal government appropriately supports safety and security for individuals with disabilities in disaster situations.

ilruNetWork

ILRU NetWork is published quarterly by IL Net, a collaborative project between ILRU and the National Council on Independent Living to provide training and technical assistance to centers for independent living and statewide independent living councils nationwide.

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Substantial support for development of this publication was provided by the Rehabilitation Services Administration, U.S. Department of Education. The content is the responsibility of ILRU and no official endorsement of the Department of Education should be inferred.

Long-Term Care: The Public's View

By Peter D. Hart Research Associates and American Viewpoint

Summary

The American public understands that the financing of long-term care is a serious policy problem and seems receptive to change. Nearly three-quarters of baby boomers and seniors are concerned either a great deal or a fair amount about paying for long-term care, according to a poll commissioned by the National Academy of Social Insurance's study panel on long-term care. Seven in ten believe that government should do more to help people meet the costs of long-term care. Even those less concerned about the problem are troubled that the current system impoverishes people before it helps them. After hearing that Medicaid covers care only after people have exhausted virtually all their own resources, 41 percent of respondents conclude that the system of paying for long-term care "is broken and needs a complete overhaul," and another 30 percent say that it needs major improvements.

Introduction

Peter D. Hart Research Associates and American Viewpoint conducted a survey from March 3 to 8, 2004, among 804 Americans age 40 and over for the Service Employees International Union and the National Academy of Social Insurance. The survey assessed this audience's knowledge of, level of concern about, and policy attitudes toward long-term care. The margin of sampling error for the survey is ± 3.5 percentage points for results based on the entire sample and higher among subgroup populations.

The survey sample is structured in generational terms, with a focus on two generations of Americans: baby boomers (age 40 to 59) and seniors (age 60 and over). Seniors, as the age cohort most likely to need long-term care, are a critically important group to study. Because political candidates, journalists, and policymakers may assume that long-term care is *only* a seniors' issue, we also wanted to explore whether baby boomers are concerned about this issue (the answer is yes). To accommodate robust samples of seniors and baby boomers, younger adults are not included in this survey sample. Given these findings among baby boomers, however, it cannot be assumed that young people are unconcerned about long-term care, and future research with that population could prove enlightening.

For the purposes of this study, long-term care is defined as care provided on a regular basis for three months or more, including providing help with personal-care tasks such as bathing or dressing, help for people who cannot perform daily activities such as cooking or taking

Peter D. Hart Research Associates and **American Viewpoint** are two of the leading survey research firms in the United States. This analysis was prepared for the National Academy of Social Insurance's study panel on long-term care.

medications, or help with nursing care such as monitoring blood pressure. Long-term care as defined in this survey can be provided in a nursing home, in a person's home by aides or family, or in an assisted-living facility.

The public is highly concerned about the affordability of long-term care and expresses a desire for the nation to make addressing long-term care costs a high priority. Most baby boomers and seniors believe that affording the costs of long-term care is difficult for most people, and that the current system of paying for it is broken and must be fixed. The public does not expect or want the government to do it all, but it would like to see the federal government do more. Adults are especially drawn to programs that give individuals and families more incentives to prepare for the potential expense of care in a nursing home, an assisted-living facility, or in their own home. Americans seek a greater partnership among families, individuals, and the government to help people meet these costs.

The survey results also shed light on the factors and forces that drive concern about long-term care, both at the personal and societal level. These findings should prove invaluable to a public education effort about the serious challenge that long-term care costs will pose for American families and the government in the years ahead.

Personal Knowledge and Concern

Americans associate long-term care with senior citizens, as more than four in five (84%) say that when they think about long-term care, senior citizens age 65 or over are the first type of people who come to mind. Just one in five (19%) first think of adults with disabilities, and only 10% initially think of children under 18 who have a disability. This is an important perception that shapes the public's attitudes toward long-term care.

Adults are asked a battery of questions to assess their personal experience with long-term care, either through their own experience or through that of a family member or close friend, to measure whether personal experience affects attitudes toward this issue. One in 12 (8%) Americans age 40 and over say that they are currently receiving some form of long-term care assistance—6% from family or friends and 2% from a nurse or paid caregiver in their home—including 6% of baby boomers and 11% of seniors (of course, residents of long-term care institutions are unlikely to be reached in a telephone survey). Another three in five (59%) indicate that they have a relative or close friend who currently receives or has received long-term care. In total, nearly two-thirds (63%) of Americans age 40 and over have some personal experience with long-term care, most of whom gained their experience through a parent or a spouse's parent (30%), or a grandparent or spouse's grandparent (12%).

One-third (32%) of adults polled say that the people they know who are receiving or have received long-term care mainly receive assistance in a nursing home, but just over one in 10 say that their relative or close friend receives care in an assisted-living facility (13%), in their home from family or friends (13%), or in their home from a nurse (11%). A third (34%) also say that their relative or close friend relies on government assistance to pay for part or all of their long-term care, and nearly all these adults say that this person had to exhaust all his or her savings to qualify for government assistance.

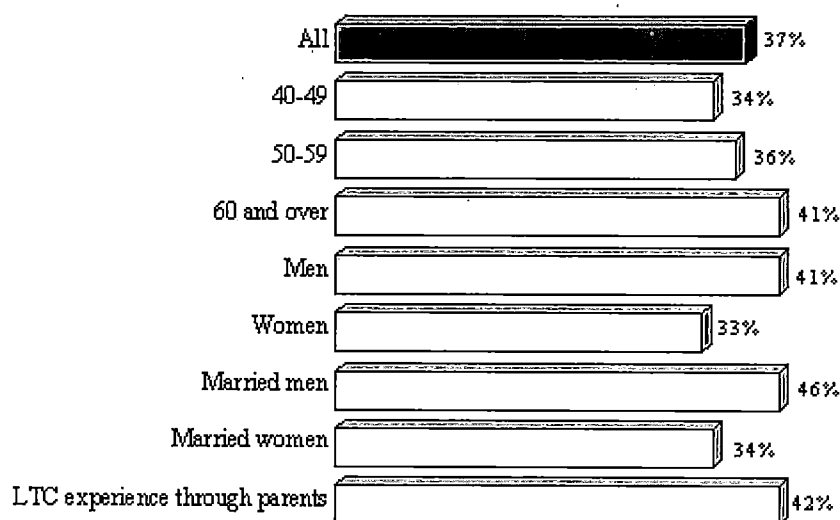
Planning and Paying for Long-Term Care

Fewer than two in five (37%) adults report that they have developed a plan to pay for their long-term care needs, compared with the 31% who admit that they have not thought about paying for their own long-term care, and the quarter (23%) who have not started planning because they do not believe that they will need long-term care in the future. Americans age 60 and over (41%) are only slightly more likely to have made plans than are adults in their forties (34%) and fifties (36%). Seniors (28%) also are slightly more likely to expect that they will *not* need long-term care compared with Americans 40 to 59 years old (20%).

Men (41%), married men (46%) especially, are more likely than are women (33%) and married women (34%) to have developed a plan to pay for long-term care should they need it. People whose parents currently receive or have received long-term care (42%) and Americans who believe that paying for long-term care is a personal responsibility rather than a government responsibility (47%) are more likely than others to have a plan. Conversely, substantial majorities of the youngest members of our sample, 40- to 49-year-olds (59%) and women age 40 to 59 (61%), as well as African Americans (68%) say that they do not have a plan to pay for their own long-term care expenses.

Planning For LTC

Proportion of Americans age 40 and over who say they have a plan to pay for LTC



One reason for the low level of planning is that most Americans do not believe that they personally will need long-term care: just 35% feel that it is very likely that they or their spouse will ever need such care. This personal expectation of need plays an important role in determining people's level of concern about this issue (and their view of policy solutions).

In the event they may need it, adults are divided over how to pay for their long-term care. One-third (32%) say that they would rely on long-term care insurance to pay for their expenses (far more than we know actually have such insurance), whereas nearly three in 10 (28%) would

rely on personal savings. Another quarter (23%) plan to rely on a government program should they incur expenses for their own long-term care, and fewer than one in 10 (8%) say that they would rely on family; 6% admit that they are not sure how they would pay for it.

We know from other surveys on this topic that the proportion of the public who think that they have long-term care insurance is a vast overestimate. In this poll, one-third of every demographic group says that they would rely on long-term care insurance to pay for their long-term care costs. A couple of demographic groups on the high end in this regard include African Americans (41%) and middle-income Americans earning between \$40,000 and \$75,000 (39%). People who believe that paying for long-term care is a personal responsibility (40%) and those who say that they have a plan to cover their costs (49%) are among the most likely to report that they will use long-term care insurance to cover their expenses. Americans in their fifties are the least likely to rely on personal savings (19%), compared with adults in their forties (32%) and adults age 60 and over (31%). Americans in their fifties also are slightly more likely to say that they would rely on a government program (28%).

Regardless of whether one has experience with long-term care, the vast majority (90%) of adults age 40 and over recognize that affording the costs of long-term care is a difficult proposition, including 62% who say it is very difficult. Affording long-term care costs is considered far more difficult than finding quality nursing home care (70% very/fairly difficult), finding quality home-care providers (63%), and finding information about how to judge quality facilities and caregivers (64%) or information on government programs that provide or help fund long-term care (55%).

People's perceptions of the coverage they have are complicated by the fact that both Medicare and private health insurance cover limited periods of nursing home or at-home care, albeit not long-term personal support. Only one-third (34%) of adults surveyed know that long-term care costs are covered by Medicaid for low-income people with no savings, 21% think that costs are covered by Medicare, 14% think that neither Medicare nor Medicaid cover costs, and another 20% admit that they are uncertain. Eight percent think that a government program other than Medicare or Medicaid covers costs. When it comes to government long-term care policies, experience is the best teacher. The people who are most likely to know that long-term care costs are covered by Medicaid are those who know someone who spent down (44%) to qualify for Medicaid or those who have a parent who currently receives or has received long-term care (45%).

Personal Concern Over Paying for Long-Term Care

Paying for long-term care is a very significant concern among the over-40 public. Nearly three-quarters are concerned either a great deal (54%) or a fair amount (18%) about paying for long-term care, either in a nursing home or at home, for themselves or for another family member. Only one in four (27%) Americans age 40 and over say that they are only concerned a little or not at all. Surprisingly, the proportion expressing greater concern about paying for long-term care is nearly identical to the proportions who are concerned with paying for medical treatment if diagnosed with a major medical illness (73%) and paying for the costs to live comfortably in retirement (75%) as one of the top issues of concern to members of this age group.

Substantial racial, education, and income differences exist about concern over affording long-term care costs. African Americans (77%) are far more likely than are whites (50%) to be concerned a great deal about affording care costs. While three in five (60%) of those with a high school education or less report this level of concern about paying for long-term care, fewer than half (46%) of college graduates are as concerned. In addition, compared with the 61% of individuals in households earning less than \$40,000 who express a great deal of concern, just 44% of those living in households with an income greater than \$75,000 are as concerned.

Interestingly, Republicans (43%) are far less personally concerned than are Democrats (63%), and this ratio holds even when controlled for socioeconomic status and race. Perhaps the most surprising finding is a non-relationship: having personal experience with long-term care (such as having a parent or other relative receive care) is not correlated at all with concern about affording long-term care. However, personal expectations concerning the likelihood that the respondent (or his/her spouse) will someday need care is positively associated with concern over paying for the costs.

Concerned a Great Deal about...

	Paying For Medical Treatment If Diagnosed With A <u>Major Medical Illness</u>	Paying For Long-term <u>Care</u>	Paying For The Costs To Live Comfortably in <u>Retirement</u>	Paying For Education For <u>Child/Grandchild</u>
	%	%	%	%
All Adults	57	54	51	31
Women	60	60	57	32
Men	54	47	45	31
African Americans	79	77	67	52
Whites	54	50	49	28
Democrats	67	63	59	38
Republicans	43	43	43	26
Less than \$40,000	66	61	61	33
More than \$75,000	42	44	38	31

Interestingly, concern does not vary much by age, with baby boomers expressing just as much concern over affording long-term care costs as do senior citizens. Baby boomers in their forties (53%) are as likely to express a great deal of concern about this issue as are baby boomers in their fifties (57%) and seniors age 60 and over (53%). Women (60%), however, are much more likely to express a great deal of concern over long-term care affordability than are men (47%), and the gap between married women (62%) and married men (45%) is even greater.

Long-Term Care as a Public Problem

In addition to the fairly high levels of personal concern, a 53% majority says that addressing long-term care costs should be a high priority *for the nation*, including 34% who say it should be a very high priority. Slightly more than a third (37%) of adults think that addressing these costs should be a moderate priority, and just one in 10 (9%) believe that these costs should be a lower priority than that. Some connection to age exists: fewer than half of 40- to 49-year-olds (46%), compared with majorities of 50- to 59-year-olds (55%) and seniors age 60 and over (58%), feel that it should be a very or fairly high priority.

A connection exists between the perception that affording the costs of long-term care is very difficult and the priority one believes that long-term care should be for the nation. For example, nearly three-quarters (73%) of those who say that these costs should be a very high priority for the country also believe that paying for them is very difficult. Comparatively, nearly two-thirds (63%) of those who believe that long-term care costs should be a fairly high priority for the country, and a smaller majority (55%) of those who believe it to be a moderate or lower priority, perceive these costs to be very difficult to afford.

Long-Term Care Priority for the Country

	<u>Very/Fairly High Priority</u> %
	%
All Adults	53
Women	55
Men	51
African Americans	81
Whites	50
Democrats	67
Republicans	37
Less than \$40,000	63
More than \$75,000	38

Many of the same differences among groups are apparent on this measure as are evident on the question of concern over affordability. African Americans (81%), Democrats (67%), those with a high school education or less (64%), and adults in households earning less than \$40,000 (63%) are much more likely than are whites (50%), adults in households earning more than \$75,000 (38%), college graduates (37%), and Republicans (37%) to believe that addressing the costs of long-term care should be a very or fairly high priority for the nation. But there also are interesting findings among Americans who have a plan in place to pay for long-term care

(48% very/fairly high priority) versus those who have not thought about paying for it (59%). Americans who think of long-term care as a personal responsibility and have taken planning steps are somewhat less inclined to see the issue as a public (or government) concern.

A number of multivariate regression analyses were conducted to uncover the factors that are most important in shaping attitudes toward long-term care as a priority for the nation. The analysis reveals that partisan preferences (revealing ideological differences) and socioeconomic status are strong predictors of concern about long-term care as a national issue. Those Americans with higher incomes, with higher levels of education, or who self-identify as Republicans are less likely to consider long-term care to be a high national priority. African Americans are more likely than are whites to rate this as a priority issue.

In attitudinal terms, two related factors emerge as powerful predictors of believing long-term care should be an important national priority: the perceived likelihood that one (or one's spouse) will need long-term care at some point in the future and personal concern about paying for it. Surprisingly, our regression model finds no correlation between personal experience with long-term care and propensity to consider it a high priority for the country. Even more immediate personal experience—those who have or have had a parent or spouse's parent in long-term care—fails to meet the threshold for a significant correlation. There also is no relationship with knowledge about government policies related to long-term care, such as the fact that one must spend down before qualifying for help from Medicaid.

Attitudes toward long-term care, then, are driven by a combination of ideology and a very personal perspective on the likelihood that one's own family will confront long-term care financing problems. Knowledge of long-term care, even knowledge gained from direct, personal experience, does not appear to affect attitudes in a significant way. This poses significant challenges for any public education effort addressing this issue.

The Role of Government

Direct questions about the public's attitude toward the current system of paying for long-term care suggest widespread discontent with the system as currently designed. After being presented with a description of current government coverage for long-term care costs, seven in 10 (71%) Americans age 40 and over feel that the current system of paying for expenses needs a complete overhaul (41%) or major improvements (30%). Only one-quarter (23%) think that the system works well just as it is or could use only minor improvements. The results show almost no difference between those with experience with long-term care (70% complete overhaul/major improvements) and those with no experience on this dimension (71%). African Americans (54%), Democrats (49%), those earning less than \$40,000 (45%), and those in their fifties (45%) are among the most likely to say that the system needs a complete overhaul. A slim majority (51%) of people currently receiving long-term care agree that the system is broken. Again, ideological outlook is clearly more important in shaping views on this matter than is personal experience with long-term care.

System of Paying for Long-Term Care

Complete Overhaul/Major Improvements

	%
All Adults	71
African Americans	72
Whites	71
Democrats	80
Republicans	63
Less than \$40,000	73
More than \$75,000	69

Given the perceived inadequacy of the current policy, it is not surprising that a strong majority (70%) of Americans age 40 and over think that the federal government should do more to help people meet the costs of long-term care; only 22% say that the government should do less or is doing the right amount. Large majorities of almost every demographic group, and even a small majority of self-identified Republicans (53%), believe that the federal government should do more in this area. African Americans (89%), Democrats (86%), and people earning less than \$40,000 (79%) are the most likely types of Americans age 40 and over to believe that the federal government should do more to help people meet the costs of long-term care, but women (74%) are more likely than are men (66%), and fifty-somethings (77%) are more likely than are those in their forties (69%) or those age 60 and over (67%) to want the government to do more. Nearly four in five (78%) people who know someone who spent down to qualify for Medicaid coverage of long-term care expenses are looking for the federal government to do more.

Should the Federal Government Do More to Pay for Long-Term Care?

Should Do More

	%
All Adults	70
African Americans	89
Whites	68
Democrats	86
Republicans	53
Less than \$40,000	79
More than \$75,000	62
Women	74
Men	66
Know someone who spent down	78

However, even Americans who think that the government should do more to help people meet these costs are not looking at the government as a panacea for paying for these expenses. By two to one, people who think that the federal government should do more also believe that paying for long-term care should be a *shared responsibility* between individuals and the government, rather than having the government provide long-term care for all through an expansion of Medicare. Three in five (60%) believe that there should be tax incentives to encourage Americans to save and purchase long-term care insurance and that the government should pay for the care of low-income people, compared with only one-third (32%) who think that additional Medicare premiums and higher taxes should be instituted to ensure that all Americans are covered. There is only a slight difference between the attitudes of baby boomers (62% shared responsibility, 33% coverage through Medicare) and those of seniors (56%, 31%) on the extent of the role the government should play.

This reluctance to have the government take on primary responsibility for financing long-term care reflects a more general skepticism about an enhanced role for the federal government. The nation continues to be divided over whether the government should be doing more to solve the country's problems (46%) or whether it already is doing too many things better left to businesses and individuals (41%).

Among all adults 40 and over, a 42% plurality wants to see the government sharing responsibility with individuals through policies such as tax incentives. In contrast, just 21% believe that the government should not do more than it does now to help people meet the costs of long-term care, and another 22% would like to see the federal government provide long-term care coverage for all Americans.

What Should be the Federal Role in Paying for Long-Term Care?

	Government Should <u>NOT Do More</u> %	Shared <u>Responsibility</u> %	Government <u>Should Provide</u> %
All Adults	21	42	22
Whites	23	41	21
African Americans	7	51	32
Democrats	8	52	40
Independents	20	62	30
Republicans	37	69	21
Less than \$40,000	14	43	28
\$40,000-\$75,000	19	46	24
More than \$75,000	33	44	14

To gauge attitudes toward the government's role in paying for long-term care expenses, adults are asked to rate how they believe the costs of long-term care should be covered in this country on a one-to-seven scale, on which a seven means that it should be strictly a government

responsibility and a one means that it should be strictly a personal/family responsibility. The public leans slightly toward a larger role for the federal government, as half (50%) have the view that paying for long-term care should be a government responsibility (a combined rating of “5,” “6,” and “7”), compared with only 28% who feel that it is an individual responsibility (a combined rating of “1,” “2,” and “3”). At the same time, most (59%) people choose a number toward the middle of the scale (a combined rating of “3,” “4,” or “5”); indicating that the majority is neither looking for solely a government solution or purely a personal responsibility solution.

The findings are almost exactly the same for those with long-term care experience (48%, 28% government responsibility) and those without (51%, 30%). Notably, Republicans and people residing in households earning more than \$75,000 lean most toward it being a personal responsibility rather than the government’s.

Balancing Government and Personal Responsibility

	Government Responsibility <u>(5-7 on a 7-point scale)</u>	Personal Responsibility <u>(1-3 on a 7-point scale)</u>
	%	%
All Adults	50	28
Whites	46	31
African Americans	75	11
Democrats	64	16
Independents	47	26
Republicans	30	48
Less than \$40,000	60	21
\$40,000-\$75,000	43	31
More than \$75,000	37	41
Experience w/LTC	48	28
No experience	51	30

Regression analysis shows many of the same relationships that we uncovered with regard to long-term care being an important national priority. Having a low income, being African American, and identifying as a Democrat all are associated with favoring a larger government role. Interestingly, the older the adult, the less likely he or she is to favor a larger government role. Once again, immediate personal experience with long-term care is not a significant predictor, but anticipation that one will need long-term care at some point in the future and personal concern about being able to afford to pay for care are predictors of a favorable attitude toward a government role.

Impact of Information

The final section of the survey is devoted to giving people information about long-term care as a national problem and measuring their reaction to it. Most of the reasons for why more must be done to help people meet the costs of long-term care are fairly compelling to Americans age 40 and over. It is important, however, to understand that this is not designed as a balanced exercise. No effort is made to present people with information that might undercut a commitment for national action, such as the size of the current federal budget deficit or the huge cost to the government of substantially expanding coverage. These questions simply are trying to determine which types of information are most compelling as reasons why long-term care should be a higher national priority.

The most convincing reasons center around the increasing number of Americans who will need long-term care in the future and the attendant costs of such a rise, as well as that people have to deplete their savings before they can receive any government assistance. The expense of private long-term care insurance as well as the dearth of individuals who possess these policies also is very convincing to most Americans 40 and over.

Americans say that recent estimates indicating that the number of elderly individuals with long-term care needs will rise by 39% by 2020 is a very convincing reason (54%) why more needs to be done to help people meet long-term care costs (another 21% say it is fairly convincing). This message is especially resonant with people who are concerned a great deal about being able to afford long-term care (66% very convincing), compared with only 40% of people who are only concerned a fair amount or less. Employing a similar theme, the message that total spending on long-term care is now \$139 billion and government estimates show that the cost will increase between two and four times in the next 20 years is very (51%) or fairly (19%) convincing to many individuals. This message is one of the most convincing among people who have yet to begin thinking about how they would pay for long-term care (59% very convincing, 20% fairly convincing).

Informing people that nursing home residents have to spend all their assets except for \$2,000 to become eligible for government help with their long-term care expenses also is a very convincing argument among a majority (54%) of Americans age 40 and over. Three in 10 (29%) say that it is just somewhat or not too convincing a reason. Adults who know someone who spent down (64%) or currently receive long-term care (69%) are much more likely than average to find this to be a compelling reason why more must be done.

Pointing out the facts about private long-term care insurance is a bit less compelling, but is persuasive to some. Half of all adults say that studies suggesting that private long-term care insurance is affordable for only 10% to 20% of elderly individuals (51%), and that only about 4% of American adults currently have a private long-term care insurance policy (48%) are very convincing reasons. Another one in five (17%, 21% respectively) say that these reasons are fairly convincing.

In general, messages about future projected growth in the numbers of long-term care patients and in the costs for long-term care are most resonant with baby boomers, essentially those whom these projections are discussing. Although the messages that work best are effective

among both men and women, women react more intensely to the range of themes than do men. Lower-income Americans and those on fixed incomes (retirees) react most strongly to messages that discuss the spend down requirement, the cost of long-term care insurance, and the average cost of nursing home care. The image conjured by informing people about the Medicaid spend down requirement is obviously troubling even for people who generally are not inclined to support more action on long-term care affordability—half of Republicans (49%) and those who say that long-term care costs are a moderate or low priority for the nation (51%) find this message very convincing.

Despite the fact that adults find many of these messages to be persuasive, after listening to an extensive case for doing more to help people meet long-term care costs, the proportion that are concerned a great deal or a fair amount about being able to pay for the costs of long-term care (74%) remains virtually unchanged from the outset of the survey (72%). The same is true for the proportions who believe that addressing this issue should be a high priority for the nation (54% at the end of the survey versus 53% at the beginning), as well as those who lean toward the view that paying for long-term care should be a government responsibility (50% rate this a “5,” “6,” or “7” at the beginning, and 49% say the same at the end of the poll).

To some extent, these attitudes are shaped by larger, pre-existing philosophical orientation on the proper role of the government versus personal responsibility. The other key factor in shaping opinion is personal expectations of the need for long-term care, together with anxiety about paying for those costs. The information tested in this survey did not really address such personal expectations, but focused mainly on national level statistics about the projected increases in the demand for and cost of care.

Whether or not attitudes change over the course of the survey, the data clearly demonstrate that Americans age 40 and over already are deeply concerned about long-term care. They believe that more must be done to help people afford these expenses. Fundamentally, Americans are looking for a balance between personal responsibility and government assistance as the nation addresses the challenge of financing long-term care.



The National Academy of Social Insurance (NASI) is a nonprofit, nonpartisan organization made up of the nation's leading experts on social insurance. Its mission is to promote understanding and informed policymaking on social insurance and related programs through research, public education, training, and the open exchange of ideas.

The Service Employees International Union (SEIU) provided financial support for the survey whose findings are described in this brief.

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Long-Term Care Financing: Models from Abroad

By Mark Merlis and Paul N. Van de Water

Summary

Achieving a long-term care system that meets individual needs and distributes costs equitably will require fundamental reform of long-term care financing and a substantial commitment of federal resources. So concludes the National Academy of Social Insurance's study panel on long-term care in its report, *Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future*.

Many other developed countries are further along the aging curve than the United States and have already made reforms to their long-term care systems. Some have adopted a universal approach to providing public long-term care insurance, while others use means testing. Their experiences illustrate different ways to balance public financing that spreads risk with personal responsibility through cost sharing, as well as methods of targeting benefits, controlling costs, and supporting caregivers. This brief highlights and updates the findings of a comparative analysis prepared for the Academy's study panel. The full analysis, which also highlights parallels with long-term care programs in the U.S. and issues in evaluating different models, is available on the Academy's website at www.nasi.org.

Types of Public Long-Term Care Programs

Some public long-term care programs cover most or all of the population, providing benefits to anyone meeting a test of disability. Others serve only people whose income and assets are below certain levels. In most countries, both local and national governments are involved in financing long-term care. In virtually all cases, beneficiaries share responsibility for their long-term care by paying premiums or cost-sharing. Private long-term care insurance is quite rare in other countries.

Social Insurance

Austria, Belgium, Germany, Israel, Japan, Luxembourg, and the Netherlands offer social insurance for long-term care. Social insurance programs cover all or most of the population and have a dedicated funding source. The German program, established in 1995, covers long-term care through the same organizations that provide health insurance (but with entirely distinct funding). The contribution rate is 1.7 percent of income (up to a ceiling), divided equally between workers or retirees and employers or

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pension funds. Starting in 2005, childless employees pay a supplementary contribution of 0.25 percent; the differential contribution rate acknowledges that raising children is one of the pillars of the long-term care insurance system, since children will be paying contributions in the future. High-income people may opt out of the social insurance system by purchasing equivalent or better private coverage. As of January 2005, the social insurance system covers 70 million Germans, and the private system covers another 9 million high-income workers and civil servants.

In Japan, everyone aged 40 and over participates in a social insurance program operated by municipalities. Half the program cost is covered by contributions or premiums, and half is covered by payments from the central, prefectural, and municipal governments. For covered workers, the contribution rate is 0.9 percent, split equally between employers and employees. People aged 65 and over pay an income-related premium. The Japanese program dates from 2000.

Social Democratic Model

The Scandinavian countries provide universal coverage through public services. Everyone is entitled to long-term care services through municipal programs funded primarily by local and regional tax revenues. The central government covers roughly 30 percent of costs in Finland and 15 percent in Sweden. The Danish central government makes no fiscal contribution. While coverage is universal, benefits or required cost-sharing may vary according to local ability to raise funds. Differences in the proportion of the population served, the level of benefits, and the level of charges have been especially high in Sweden and Denmark.

Means-Tested Systems

Australia, New Zealand, the United Kingdom, and many other countries rely primarily on means-tested programs financed from general taxation. In the United Kingdom, the National Health Service covers nursing care in the community and in nursing homes. Non-medical long-term care is furnished by localities on a means-tested basis (except that there is no means testing for personal care in Scotland). Funding comes primarily from the central government, however, but also partly from local taxation and user charges.

Hybrid Systems

A simple dichotomy between universal programs and programs aimed at the poor does not adequately characterize some systems. A universal program can cover everyone but vary benefits according to income. France's personalized independence allowance (APA), or autonomy pension, provides cash payments to be used for long-term care services for people age 60 and over. A maximum benefit amount is specified for each of four levels of disability. The benefit is reduced according to a sliding scale based on income: the highest-income participants receive only 10 percent of the maximum benefit for their disability level. The central government and the elected councils in each department jointly fund the benefit, which took effect in 2002.

Similarly, a means-tested program may have standards so generous that much of the population is eligible. Israel's social insurance program provides full benefits to aged people who meet disability tests and whose income is no higher than the average wage (or, for a couple, 1.5 times

the average wage)—a test met by many pensioners. A single person with income more than 1.5 times the average wage or a couple with income more than 2.25 times the average receive no benefits. In 2004, 113,500 Israelis received long-term care insurance benefits, compared to 722,000 old-age pensioners.

Finally, some countries have both a universal social insurance program and a means-tested social assistance program. In Germany, people who cannot meet the cost-sharing requirements for nursing home care are helped by local means-tested programs, which are financed by the states. Austria and Belgium have similar systems.

In Canada, each province runs its own long-term care system, with federal funding in the form of a block grant shared with health and education programs. Home care tends to be a universal entitlement, while provinces vary in the extent to which they impose means-testing for institutional services.

Controlling Spending

No nation offers a public long-term care program that provides an unlimited entitlement to services without a strategy for managing costs. Some countries limit benefits on a per person basis. Others stay within a fixed budget by adjusting eligibility thresholds, limiting services, or establishing waiting lists.

Limited Entitlements

Germany and Japan provide services (or, in Germany, an optional cash alternative) up to a fixed amount per person based on level of disability. These programs are limited entitlements whose costs are fairly predictable in the short term. They may incur higher spending if more people participate, but not because people use more costly services than expected.

France's autonomy pension is an example of a limited entitlement that actually faced budget overruns because of unexpectedly high participation. Costs turned out to be nearly 50 percent higher than estimated, and the government responded by tightening eligibility and lengthening the waiting period before benefits are available.

Budgeted Systems

The Scandinavian long-term care systems nominally provide an entitlement to all appropriate services to everyone who needs them. In practice, however, the local governments that operate the program adjust the criteria for eligibility to fit available finances. Implicit rationing may also arise if services are covered but unobtainable. For example, at the start of the German program, 30 percent of the home care budget could not be spent because there was no one to provide care. The Organization for Economic Cooperation and Development (OECD) reports that the Netherlands has waiting lists for both home and institutional care.

Budgeted systems may also ration informally. In England, where localities provide services under fixed allocations from the central government, there are no set eligibility or benefit standards. Needs are assessed and services doled out on an *ad hoc* basis; people cannot be certain what kind of help they might receive.

Cost Sharing

Beneficiaries must usually contribute to meeting the cost of both home care and institutional care. This requirement retains a measure of personal responsibility for long-term care and holds down costs by deterring utilization.

For home care, many countries impose some form of fixed payment per visit—often amounting to some 10 percent to 15 percent of cost and subject to income-based exemptions or sliding scales. In the Japanese social insurance system, beneficiaries pay only 10 percent of the costs irrespective of their income. Germany does not impose explicit co-payments but has implicit cost sharing, since the amount of home care provided at each level of benefit falls short of the estimated need. France's disability-based cash allowances are reduced by a fixed amount based on income; this financial participation is not linked to service use or expense.

Cost-sharing tends to be larger for institutional care than for home care, partly because people in institutions have fewer additional demands on their resources. Some systems, such as the U.K., have spend-down regimes for nursing home care comparable to that in the U.S. Others, such as Belgium, Finland, and Sweden, impose cost-sharing that consumes a substantial fraction of income. Many countries expect nursing home residents to pay the costs of accommodation—rent, meals, utilities, housekeeping, laundry, and other ordinary expense of living—unless they are receiving social assistance. In some cases, the accommodation charge is related to the level of the public pension.

Evaluating Need and Targeting Benefits

Both public and private long-term care programs must have a way of determining who is sufficiently disabled to qualify for benefits. Programs that vary cash or service benefits by level of care must also have ways of classifying participants; these systems vary in the number of benefit tiers used and the range of benefits for each tier. To determine eligibility or care level, some systems use explicit criteria, such as requiring assistance with a given number of activities of daily living (ADLs) or needing a certain number of hours of care. Others allow more discretion to decision-makers. Entitlement programs tend to use explicit criteria, while budgeted programs are more likely to rely on discretionary judgments, which can be adjusted to meet funding targets.

Explicit Criteria

Systems using fixed criteria vary considerably in their stringency. The German social insurance program is relatively strict. To be eligible for the lowest level of benefits, a person must need assistance at least once a day with two ADLs and require at least 90 minutes of assistance per day. To receive the highest (third) level of benefits, a person must need continual assistance averaging at least five hours a day. For the French autonomy pension, needing assistance with three ADLs is the minimum standard of eligibility. The highest (fourth) level of benefits is reserved for those who have lost both physical mobility and mental acuity.

In contrast, Japan offers a minimal benefit to people who need as little as 29 minutes of care a day and provides six different levels of benefits. For in-home benefits, an automated program considers 73 individual characteristics (including ADLs, instrumental ADLs, and cognitive

measures) in assigning applicants to one of six care levels. Furnishing supportive services to less disabled individuals is specifically designed to slow deterioration and prevent premature institutionalization.

Discretionary Judgments

To avoid replacing informal care, some programs combine disability standards with consideration of the availability of family supports. Someone who is highly disabled but living with family members might require services only intermittently, while someone living alone might need help even with a less severe disability. Under such a system, budgetary pressures may result in shifting burdens to family caregivers. In Sweden, for example, municipalities rarely furnish assistance to elderly women who must care for their husbands.

Although most countries with social insurance for long-term care have explicit criteria for eligibility, the Netherlands relies on a rather subjective assessment. Eligibility for benefits is determined through “holistic” evaluations by teams that may include nurses, social workers, and other professionals. The team considers the level of disability, the home environment, and the availability of informal care. There is no uniform instrument for these assessments, and the teams have a high degree of professional discretion.

Home-Care Benefits

Increasingly, public long-term care programs are providing more paid home care, with the goal of allowing people to remain in the community and avoid costly institutionalization as long as possible. Home care programs vary along two dimensions. The first is the *degree of consumer direction or autonomy*—from systems in which an agency or care manager makes all decisions to systems in which individuals decide what they need and where to get it. The second is the *type of benefit*—ranging from provision of formal services from recognized providers, through service budgets that may be used to pay formal and informal providers but may not be retained as income, to unrestricted cash grants.

Under traditional programs that pay for in-kind services, agency-selected providers furnish services under an agency-approved care plan. This arrangement can apply either in a social insurance program (as in the Netherlands) or in a means-tested program (as in the UK).

At the other extreme, exemplified by the French autonomy pension and a similar cash option under the German system, the individual receives funds that may be used to pay anyone for any service or that may be retained as income. Under the German social insurance system, participants may choose between in-kind benefits and a cash grant. The in-kind benefit allows substantial autonomy; benefits may be obtained from licensed providers of services up to specified monetary limits. Alternatively, people opting for a benefit in cash may use it to pay family caregivers or in any other way they see fit. The cash benefit is set to equal about half the benefit in kind for a given disability level.

Between these two poles are programs that pay only for services but give the consumer some discretion in what services will be provided or by whom. In the Japanese social insurance system, for example, after the municipality determines the needed level of care, a care manager

draws up a care plan. Beneficiaries may acquire services from approved providers in an amount up to the budget ceiling for their level of care. In the Netherlands, following reforms in 2003, new home-care users have been offered the option of a consumer-directed budget in place of direct services. In Denmark, beneficiaries may choose providers but do not receive a service budget.

Supporting Caregivers

Throughout the world, relatives, friends, and other unpaid caregivers provide a substantial amount of long-term care. In part to hold down spending on more costly forms of care, several countries have recently adopted policies to support informal caregivers, including the provision of cash allowances, respite care, and pension credits.

The German and French cash benefits may be used to pay family caregivers. In addition, the German system furnishes up to four weeks of in-home respite care or short-term institutional care to provide relief to informal caregivers. Training is made available for unpaid caregivers, and the long-term care insurance funds may make public pension contributions on their behalf.

Several countries, including Australia, Canada, Ireland, Sweden, and the United Kingdom, have introduced payments to caregivers to make up for some of their foregone earnings. The U.K. offers a Carer's Allowance to people who spend at least 35 hours a week looking after someone who is receiving or has applied for certain benefits based on disability. People receiving a Carer's Allowance for an entire year also receive credits under the U.K.'s earning-based supplemental pension as if they had annual earnings of £12,100 (\$21,900).

Conclusion

Analysis by the Organization for Economic Cooperation and Development finds a growing number of countries with universal public plans for financing long-term care. Public protection, the OECD reports, does not imply the absence of private obligations, such as cost sharing and out-of-pocket spending, nor does it imply unlimited services or exploding costs. Rather, it aims to strike a fairer balance between public and private financing—relating personal contributions to ability to pay and targeting benefits to the population in greatest need.

Many of the public long-term programs discussed in this brief and analyzed by the OECD are relatively new or have been recently modified. As experience accumulates, further analysis would be useful to find out how well these programs are working, how much they are spending, how many people they are serving, what changes are being considered, and what additional guidance they may offer in developing a better long-term care policy for the United States.

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The National Academy of Social Insurance (NASI) is a nonprofit, nonpartisan organization made up of the nation's leading experts on social insurance. Its mission is to promote understanding and informed policymaking on social insurance and related programs through research, public education, training, and the open exchange of ideas.

The Robert Wood Johnson Foundation provided the primary financial support for this project. Other funders include the TIAA-CREF Institute, the Service Employees International Union, GE Financial Assurance, and the John D. and Catherine T. MacArthur Foundation.

Also of interest from the
National Academy of Social Insurance website at
www.nasi.org...

Health and Income Security Brief No. 8 *Long-Term Care: The Public's View*
by Peter D. Hart Research Associates and American Viewpoint, November 2005

Health and Income Security Brief No. 7 *Increasing the Early Retirement Age Under Social Security: Health, Work, and Financial Resources*
by Michael V. Leonesio, Denton R. Vaughan, and Bernard Wixon,
December 2003, 10 pp.

Health and Income Security Brief No. 6 *When Should Medicare Coverage Begin?*
by Richard W. Johnson, December 2003, 12 pp.



Medicare Brief No. 12 *Payment and Participation: A Renaissance for Medicare's Private Health Plans*
by Reginald D. Williams II, May 2005, 11pp.

Medicare Brief No. 11 *Medicare and Communities of Color*
by Reginald D. Williams II, November 2004, 9pp.

Medicare Brief No. 10 *The Unique Needs of Medicare Beneficiaries*
by Reginald D. Williams II, September 2004, 9 pp.



Social Security Brief No. 20 *Social Security Finances: Findings of the 2005 Trustees Report*
by Virginia P. Reno and Anita Cardwell, March 2005, 4 pp.

Social Security Brief No. 19 *Social Security: What Role for Life Annuities in Individual Accounts? Issues, Options, and Tradeoffs*
by Virginia P. Reno and Joni Lavery, March 2005, 12 pp.

Social Security Brief No. 18 *Options to Balance Social Security Funds Over the Next 75 Years*
by Virginia P. Reno and Joni Lavery, February 2005, 16 pp.

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Nita Merrick Weil

Nita Merrick Weil, beloved mother, grandmother, and former director of volunteer services at TIRR, passed away Friday, December 9, 2005 at her home after a long illness. She was 75.

Having survived polio in the early 1950's, Nita moved from New Orleans, Louisiana to Houston, Texas in 1959. As a patient of the Southwest Poliomyelitis Respiratory Center, presently known as TIRR (The Institute for Rehabilitation and Research), Nita developed a close relationship with physicians Dr. Carlos Vallbona, and Dr. William A. Spencer, founder of TIRR. These physicians served not only as medical advisors, but as trusted friends as she transitioned from patient to employee. Nita began her employment with TIRR at the request of Dr. William A. Spencer. Nita accepted and was employed for more than 10 years as a receptionist. In 1968, Nita became the director of volunteer services at TIRR, a position she held until her retirement in 2002. After 43 years of volunteer service she retired from her position as director, but continued to contribute in community organizations whose efforts were to improve the quality of life for disabled persons.

Nita will be best remembered as a take-charge person. She organized patient programs and activities, and coordinated a group of volunteers that has served TIRR for more than 45 years. Nita never shied from the challenges that faced her, and applied that conviction professionally as well as personally.

Nita's contribution was not just felt at TIRR but she became a viable spokesperson for polio survivors and persons with disabilities within the community. She served as a past president of the Texas Polio Survivors Association, and was instrumental in establishing the Metrolift bus service for the disabled in Houston. She was also one of the founding members of the Houston Coalition for Barrier-Free Living, and served on the Houston committee to observe the International Year of Disabled Persons. In 1981, she was awarded the Book of Golden Deeds Award from the Exchange Club of Houston. Nita was recognized for her efforts to improve the quality of life for disabled citizens in Houston. In that Book of Golden Deeds, two letters of tribute were submitted from her trusted friends and medical advisors Carlos Vallbona, M.D. and William A. Spencer, M.D.. An - excerpt of their tributes are shared in honor of Nita.

"I have known Ms. Weil for 25 years. I met her when I was a young resident. In spite of circumstances, she appeared to have a zest for life and a desire to be active and productive.... which I could not clearly understand at the time. It was most appropriate that Dr. Spencer offer Nita a job as a receptionist when the Institute opened. Dr. Spencer felt that in her prominent position she would illustrate what it meant to be disabled, and what is most important, what it meant to be a rehabilitated person.... we saw in her that severe disability could not deter the human spirit and that it was indeed possible for a person to achieve a fulfilling life and to render productive services to the community."

Carlos Vallbona, M.D.

May 1981 - Letter of Tribute submitted to the Exchange Club Book of Golden Deeds on behalf of Nita Weil 1981 recipient

"She has a special touch with people and a remarkable perception of needs, thus treating them with grace and sensitivity. What would prove a handicap to many, is not for Nita. Over the years, she has garnered every possible resource and has worked energetically to elevate and refine the quality of life for the disabled and handicapped person in our community. Nothing deters her from her work! She is a perfect example of compassion, unselfishness, patience and just plain love."

William A. Spencer, M.D., founder of TIRR

May 1981 - Letter of Tribute submitted to the Exchange Club Book of Golden Deeds on behalf of Nita Weil 1981 recipient



Nita Merrick Weil continued

In 1983, Nita was recognized again for her volunteer service and was awarded the Governors Award for Outstanding Service. This award was presented to her for her contribution at TIRR, which encouraged and nurtured volunteers in a substantial way. Nita was an inspiration to all who knew her for her courage, kindness, and ever-present smile.

Nita is survived by her son, William D. Weil, II; daughter, Shelley W. Caspary (Don); brother, Robert W. Merrick; sisters, Patricia M. Brinson and Susan M. Harberson of New Orleans; four grandchildren; her aunt, Paula Williams, and close cousin, Caroline W. Zack.

A memorial service to celebrate her life will be held Thursday, December 15, 2005, at 2:00 p.m. in the chapel at George W. Lewis & Sons Funeral home, 1010 Bering Drive, Houston, Texas. Burial will be at Lake Lawn Mausoleum in Metairie, La., at a later date. In lieu of flowers, the family requests that memorial contributions be made to TIRR Foundation.

An Inpatient Holiday Party Thank You

From Jean Herzog, Ph.D., executive VP & COO, TIRR

THANK YOU to all the staff and volunteers who helped to make the **Inpatient Holiday Party** happen on Sunday, December 11. So many people participated it's impossible to name everyone. It was a huge success, with so many more family members able to come than when we've had it during the week in years past. Santa and Mrs. Claus (**Jerry and Peggy Stone**) and the Stone Family elves were a hit as usual, and we had clowns, the magic of **Bill Elsesser** from Marketing, our DJ, the music of the **Stratford High School Cello Choir** under the direction of **Dr. Michael Alexander**, and lots of goodies. Staff members and volunteers made everything run smoothly and safely. Thanks again to everyone for helping spread some cheer for the holidays to our inpatients and their families!

A Town Hall Thank You

Also from Jean Herzog

Thank you to all the staff who have been able to attend the Town Halls. It was a tight schedule, but many folks were able to come hear about our negotiations with the University of Texas Health Science Center at Houston, and with Memorial Hermann Healthcare System. For those of you who were not able to attend, please touch base with your manager for the current information. We will schedule Town Halls again in the first quarter as things progress, and I look forward to seeing you there!

Length of Service Corrections

We apologize to the following folks for missing them or stating their work location incorrectly in the last MidWeek:

- 15 years Patt Kash, Baylor
- 5 years Rene Mickens works on Patient Care Unit 5
- 5 years Sunil Kothari, M.D., Baylor
- 5 years Teresa Kaldis, M.D., Baylor

Length of Service Thank You

A thank you goes out to everyone who participated in the Service Awards Receptions at TIRR Rehabilitation Centers-Greenway Plaza and TIRR on Friday, December 9. They were fun gatherings and a great time to celebrate staff that have been with a TIRR Systems entity for 5, 10, 15, 20, etc. years of service. Also, a special thank you to **Fredia Conley**, Human Resources for coordinating the events. Great job!



Jeff Wissel-Littmann, president, TIRR Rehabilitation Centers and five-year length of service recipient, Danie Nguyen, physical therapist, TIRR Rehabilitation Centers-Greenway Plaza, chat during the reception at Greenway Plaza.



Seated and ready to go at the TIRR Service Awards Reception are, in the foreground, Roxy Funchess, administrative secretary, and five-year length of service recipient Maria Rosario Del Bosque, project associate, both from TIRR ILRU and in the background are five-year length of service recipients Rafferty Laredo, senior occupational therapist and Patricia Tully, senior occupational therapist, both from TIRR Therapy Services.

Thought Of The Week

Everybody can be great... because anybody can serve. You don't have to have a college degree to serve. You don't have to make your subject and verb agree to serve. You only need a heart full of grace. A soul generated by love.

— Martin Luther King, Jr.

Deadline this Friday - TIRR Systems' Employee Benefits for 2006

TIRR Systems, Human Resources is pleased to present your employee benefits program that will be effective January 1, 2006!

There will be some changes to the medical and dental plans beginning January 1, 2006. The plans, including changes, are highlighted below.

While the cost of providing health care coverage continues to escalate at a rate in excess of \$750,000 per year, TIRR Systems will be absorbing the entire rate increase in the United Healthcare medical plan for 2006; therefore, ***your employee contributions in the medical plan will remain the same.***

Further, to simplify administration, you will NOT need to complete enrollment forms if you are NOT making changes to your medical or dental plan choices. You will NEED TO COMPLETE ENROLLMENT FORMS IF YOU ARE PARTICIPATING IN THE HEALTH CARE OR CHILD CARE FLEXIBLE SPENDING PLANS.

Plan Highlights and Changes

Medical Plan - with United Healthcare

- ◆ Deductibles will remain the same.
- ◆ Coinsurance will be changing to 80% in network and 60% out of network.
- ◆ Out-of-pocket maximums will be changing to \$4,000 in network and \$8,000 out of network (max of 2 per family)
- ◆ Office visit co-pays for primary care physicians will remain at \$20 per visit. Office visit co-pays for specialists will change to \$40 per visit.
- ◆ Prescription drugs will remain the same.

Eligible Employees Working 32-40 Hours Per Week	Medical Insurance Monthly Rate
Employee Only	\$80
Employee + One	\$175
Employee + Family	\$240

Eligible Employees Working Less Than 32 Hours Per Week	Medical Insurance Monthly Rate
Employee Only	\$125
Employee + One	N/A
Employee + Family	\$450

The employee contributions for the medical plan will remain the same.

Dental Plans - with Guardian

DHMO - No changes to this plan.

PPO

- ◆ Coinsurance of 100% for preventive services, 80% for basic services, 50% for major services and 50% for dependent child orthodontia will stay the same.
- ◆ Calendar Year Max and Orthodontia Lifetime Max will stay the same.
- ◆ Calendar Year Deductible will change to \$75 per person (max of 3 per family)

All Eligible Employees	New "DHMO" Dental Monthly Rate	New "PPO" Dental Monthly Rate
Employee Only	\$9.35	\$28.33
Employee + One	\$15.18	\$62.21
Employee + Family	\$23.79	\$95.75

The premiums for both dental plans will minimally increase 5%.

Annual Enrollment Information

This year all enrollment information will be available on TIRR Systems G-Drive/Global/HR/Benefits/2006.

Benefit Summary Information will be:

- ◆ 2006 Plan Year Comprehensive Benefit Summary
- ◆ UHC Benefit Summary (including RX)
- ◆ Guardian Voluntary "Dental HMO" and "PPO" Plan Summaries
- ◆ Flexible Spending Account (FSA) Summary of Information - Health Care Account - \$5,000 maximum; Dependent Care Account - \$5,000 maximum
- ◆ Voluntary Life Insurance Information

In addition to the summary material, there will also be 3 enrollment forms available on G-Drive/Global/HR/Benefits/2006. If you need to use any of the forms, print a hard copy, complete and return to Human Resources.

Forms Information will be:

Medical/Dental Change Form - If you would like to make changes in either your medical or dental plan elections, you must complete this form. You DO NOT need to complete this enrollment form if you do not want to make any changes in either the medical or dental plan.

Flexible Spending Account (FSA) - Elections in the FSA Plan are not automatically carried forward. If you would like to enroll or re-enroll in the FSA plan for 2006, you MUST complete this form.

Voluntary Life Insurance Plan - If you would like to enroll or change your election in the voluntary life insurance plan, you must complete this form. You DO NOT need to complete this enrollment form if you do not want to make any changes in your voluntary life plan.

NOTE: If you do not have access to TIRR Systems G-Drive, please contact the Human Resources Department (HR) to pick up a paper copy of the materials and forms.

You will need to return any applicable enrollment forms to HR no later than Friday December 16, 2005. If you have any questions, please call HR at 713-799-7027 or Marwah Abdalla with Madison Benefits Group at 713-693-1666.

MEMORANDUM

TO: ALL TIRR SYSTEMS EMPLOYEES

RE: 2006 Limit Changes for TIRR Systems Employees' Savings and Investment 403(b) Plan

FROM: Beverly Schaffer/Director/Human Resources (HR)

Effective 1-1-06, the federal government has once again offered a great option to employees who are currently participating or would like to start participating in a qualified retirement plan. For the year 2006, the new maximum contribution amount has been increased from \$14,000 to **\$15,000 annually**.

The **TIRR Systems Employees' Savings and Investment 403(b) Plan** provides you with an opportunity to save any amount from \$10.00 per payroll period up to the \$15,000 per year by making pre-tax contributions. For those employees who are not yet taking advantage of this excellent benefit- - **DON'T HESITATE- - - START SAVING TODAY!!** TIRR Systems provides this plan solely to assist you in planning for a more secure and stable future.

If you are currently in the plan, consider increasing your contribution amount. You may pick up a Principal form in HR or go online to G-Drive/Global/Human Resources/Forms. To take full advantage of this option, send or bring the form to the HR department **on or before Sunday, December 18th** (the beginning of first payroll period for January, 2006).

If you have not yet enrolled in the plan, come by the HR office and complete the quick and easy paperwork. Start your year off right by belonging to the **TIRR Systems Employees' Savings and Investment 403(b) Plan**. You'll be glad you did!

Did You Know...

...The following folks joined TIRR Systems during the month of December. Welcome!!

Sylvia Trevino, registered nurse, TIRR Patient Care Unit 6; **Florence DeForest**, liaison nurse, TIRR Admissions; **Katherine Corley**, therapy aide, TIRR -Therapy Services; **Mandy Heintz**, physical therapist, TIRR Therapy Services; **Vanessa Sipp**, business office coordinator, TIRR Kirby Glen; **Rhonda Brown**, physical therapist assistant, TIRR Rehabilitation Centers-Greenway Plaza; **Joyce Williams**, clinical application coordinator, TIRR Systems Information Technology; **Nedra Hale**, registration assistant, TIRR Out-patient Clinic

... **Lex Frieden**, TIRR senior vice president of grants administration and chairperson of the National Council on Disability participated in a released report to the United States Congress and the Social Security Administration that called for changes to get more people with disabilities who receive federal benefits back to work.

... **Beth Green**, vocational coordinator, TIRR Challenge Program, received the following compliment from Liz Foley, Volunteer Services Manager, Gulf Coast Regional Blood Center. This was a message passed on to Liz from one of the supervisors at the Blood Center for whom a Challenge group had just completed a project. Beth takes clients to the Blood Center for the community service group, a vocational reintegration intervention. "...Thank you again for TIRR's help. They were excellent as usual and today they finished every one of the boxes! I am so grateful for their help and really enjoy working with Beth and her groups! It feels good to have a mutually beneficial relationship with them, because they help us while we help them during their time of recovery. I appreciate all that the volunteers and your group do for us. Thank you! See you in January...Happy Holidays!"

... **Bernie Silver**, Ph.D., director, TIRR Psychology/ Neuropsychology, published a book review in the December 2005 issue of Brain Injury. The citation is: Silver, B. Pediatric Life Care Planning and Case Management, Brain Injury, December 2005; 19 (13): 1177.

3rd Thursday Presentation

Title: **Deep Brain Stimulation**
Presenter: **Nikki Morton, M.P.T.**
Date/Time: **Thursday, December 15, 12 p.m. to 1 p.m.**
Place: **Private Dining Room A& B**

REDS Presentation

Topic: **The Origin of Spasticity in Spinal Cord Injury Patients**
Speaker: **Milan Dimitrijevic, M.D.**
Date/Time: **Friday, January 13, 12 p.m. - 1 p.m.**
Location: **7th floor conference room of BCM's Faculty Center. Lunch will be provided for the first 15 persons attending.**

Birthdays

12/14 **Christie Koudela**, TIRR Rehabilitation Centers-Sugar Land
12/14 **Joyce Dixon**, TIRR Patient Care Unit 3
12/15 **Graciela Castillo**, Environmental Services
12/16 **Isabel Mendoza**, TIRR Rehabilitation Centers-Greenway Plaza
12/17 **Carrie Baldwin**, TIRR Patient Care Unit 3
12/17 **Jacqueline Mendoza**, TIRR Case Management
12/17 **Sandra Jochen**, TIRR Systems Administration
12/18 **Joseph Riley**, TIRR Patient Care Unit 3-C
12/18 **Leslie Robinson**, TIRR Social Work
12/18 **Patty Valle**, TIRR Admissions
12/19 **Horace Nelson**, TIRR Systems IT
12/19 **Ida Susberry**, TIRR Patient Care Unit 3-C
12/19 **Patricia Tully**, TIRR Therapy Services
12/19 **Tomas Gavidia**, Food & Nutrition
12/20 **Cathy Robinson**, TIRR Urodynamics
12/20 **Elisa Martin**, TIRR Rehabilitation Centers-Customer Service Center
12/20 **Shirin Sarkari**, UT TX Med. School, Div of Clinical Neurosciences
12/21 **Diane Traconis**, TIRR Patient Care Unit 4
12/21 **Laurie Redd**, TIRR ILRU
12/21 **Lisa Hartman**, TIRR Therapy Services
12/21 **Michael Edgerly**, TIRR Rehabilitation Centers-Mid-County

Christmas Carol Quiz

Below is the classic Christmas Carol Quiz, seen in many past issues of the TIRR MidWeek, for your annual holiday cheer. Answers at the end of this MidWeek. Enjoy!

1. Quadruped with Crimson Proboscis
2. Eight p.m. to Six a.m. Without Noise
3. Minuscule Hamlet in The Near East
4. Ancient Benevolent Despot
5. Adorn the Vestibule
6. Exuberance Directed to the Planet
7. Listen, Aerial Sprites Announcing
8. Trio of Monarchs
9. Yonder In the Hay Stack
10. Cherubim Audited from Aloft
11. Assemble, Everyone Who Believes
12. Hallowed Post Meridan
13. Fantasia of a Colorless December 25
14. Tin Tintinnabulation
15. A Dozen Twenty-Four Hour Yule Periods
16. Befell During the Transparent Bewitching Hours
17. Homo Sapien of Crystallized Vapor
18. Desire a Pair of Incisors on December 25
19. I Spied My Maternal Parent Osculating
20. Perambulating Through a December Solstice Fantasy

Positive Behavioral Support Program

Date	Day	Location
Jan 19	Thu	Clinic Building, 2 nd Floor, Nursing Classroom
Feb 16	Thu	Clinic Building, 2 nd Floor, Nursing Classroom

Classes are individually posted in Outlooks' *Public Folders/All Public Folders/Global Training/2 PBS Training*. PBS Registration: Contact Rennie Swift, HR, by phone at: 281-669-0454 or e-mail.

CPR Recertification Classes

Date	Time	Location
Friday, December 30	9 a.m.-12:30 p.m.	TOTS/Challenge
Friday, January 20	9 a.m.-12:30 p.m.	TOTS/Challenge
Friday, February 24	9 a.m.-12:30 p.m.	TOTS/Challenge

Note: This is a recertification class. Please bring your most current CPR Card to class for verification.

Instructor: Marilyn MacFarlane, RN, operates a CPR training program and works at the Veteran Administration Hospital.

Cost: \$30 per person payable in check (made out to Marilyn MacFarlane) or exact cash. Money is to be paid to the Instructor at the beginning of class.

HR Please be sure you give HR a copy of your renewed certification.

Registration: Contact Rennie Swift, HR, at phone: 281-669-0454 or e-mail.

CPR Training Centers: A current listing of CPR Training Centers is located in Outlook in *Folder Lists/Public Folders/All Public Folders/Global Training/1 CPR Training*

Save This Date!

Baylor College of Medicine / The University of Texas Medical School at Houston Physical Medicine & Rehabilitation Alliance announces the 4th Annual William Blocker lecture to be held on Friday, February 3, 2006, at 8 a.m. The guest lecturer will be Robert Rondinelli, M.D. The topic is *Impairment Ratings and Disability Evaluation*. Please make plans to join us.

For more information, contact the PM&R Education Office at (713) 799-5034 or Karstena@bcm.edu.

Residents and Fellows Pager Numbers

To contact TIRR RESIDENT ON CALL, page the "on-call pager" at 713-919-4366. PM&R Education Division (713-799-5033) coordinates the on-call schedule with the PM&R chief residents.

Attending Physicians	Residents	Pager
Dr. Srinivasan	Dr. Jamie Guyden	713-919-2448
Dr. Kaldis	Dr. Natasha Eaddy	713-919-3002
Dr. Donovan/Dr. Latorre	Dr. Margaret Coon	713-919-9860
Dr. Parsons	Dr. Gabriel Williams	713-919-9634
Dr. Ivanhoe	Dr. Nneka Ifejika	713-919-1890
Dr. Fadia/ Dr. Kothari	Dr. Eddyme Danger	713-919-5037
Dr. Tastard/Shah	Dr. Shana Margolis	713-317-7990
Dr. Francisco (outpatient only)	Dr. Matthias Weiderholz, November/ Dr. Meilani Mapa in December	713-317-7995

For the most up-to-date version of the ATTENDING Physician Call Schedule, please refer to the printed copy distributed by Donna Jones, PM&R Administration Office, Baylor PM&R at 713-799-5086. (For RESIDENT on-call, page on-call pager number (713-919-4366) or contact PM&R Education Division at 713-799-5033)

Plastic Surgery/Baclofen Pump Issues

Lalita Thompson, RN, at ext. 5741 pager 713-833-9293.

20.	Walking in a Winter Wonderland
19.	I Saw Mommy Kissing Santa Claus
18.	All I Want For Christmas is My Two Front Teeth
17.	Frosty the Snowman
16.	It Came Upon a Midnight Clear
15.	The 12 Days of Christmas
14.	Silver Bells
13.	White Christmas
12.	O' Holy Night
11.	O' Come All Ye Faithful
10.	Angels We Have Heard on High
9.	Away in a Manger
8.	We Three Kings
7.	Hark, the Herald Angels Sing
6.	Joy to the World
5.	Deck the Halls
4.	Jolly Old St. Nicholas
3.	O' Little Town of Bethlehem
2.	Silent Night
1.	Rudolph The Red-nosed Reindeer
1-4 Correct:	Surely you jest?!!
5-9 Correct:	Are you sure you have the right holiday?
10-14 Correct:	You could use something in your stocking!
15-20 Correct:	You don't need any yuletide spirit!

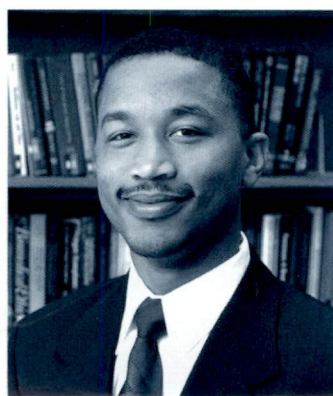
Christmas Carol Quiz



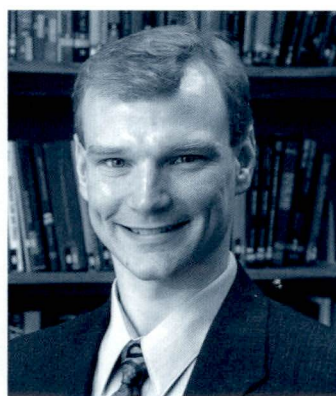
HEALTH LAWNEWS

A QUARTERLY PUBLICATION OF THE UNIVERSITY OF HOUSTON HEALTH LAW & POLICY INSTITUTE, ESTABLISHED 1978

Institute Places 2002-2003 Health Law & Policy Fellows with Texas Legislature



Timothy Carter



Christopher Lewis



Sheri J. Sanders



Carissa Waida

The Health Law & Policy Institute's Fellowship Program is an important component of the Institute's state-funded research initiative. Fellows are typically University of Houston Law Center graduates with health law and policy expertise. They provide staff support for members of the Texas Legislature serving on health-related committees. The four legislative fellows, who took their posts in Austin, Texas at the beginning of September, are Timothy Carter, Christopher Lewis, Sheri J. Sanders, and Carissa Waida.

Timothy Carter has a B.S. from Prairie

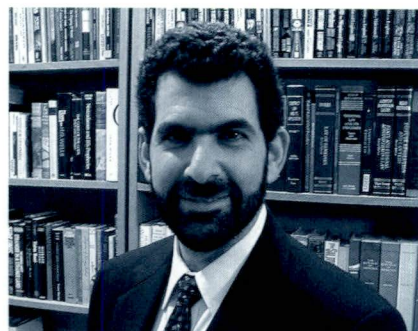
View A&M University and a J.D. from the University of Houston Law Center. Mr. Carter works for the House Public Health Committee.

Christopher Lewis received his B.A. at Duke University and his J.D. at the University of Houston Law Center, and he is working toward his M.P.H. at the University of Texas Health Science Center. Mr. Lewis is assigned to Representative Garnet Coleman. Representative Coleman is Vice Chair of the House Public Health Committee.

Sheri J. Sanders holds a B.A. from the University of Texas and a J.D. from the University of Houston Law Center. Ms. Sanders works for Senator Mario Gallegos, Jr. Senator Gallegos is a member of the Senate Health and Human Services Committee.

Carissa Waida received her B.S. at Texas Tech University, and she is currently a J.D. candidate at the University of Houston Law Center. She is working for the Senate Health and Human Services Committee.

Paul Arshagouni Joins Institute Research Faculty



The Health Law & Policy Institute welcomes Paul G. Arshagouni, Assistant Research Professor, to the University of HEALTH LAW NEWS

Houston Law Center. Professor Arshagouni is coming to us from Sidley Austin Brown and Wood, LLP, in Los Angeles, where he practiced in the firm's health care group. He received his B.A., M.P.H., and J.D. at the University of California at Los Angeles and his M.D. at the University of California, Irvine College of Medicine.

In this interview, the Health Law & Policy Institute introduces you to Professor Arshagouni.

Welcome to the University of Houston,

Professor Arshagouni. What drew you to the University of Houston Law Center?

I first heard of an opening here from a friend of mine who teaches health law at Loyola Law School in Los Angeles. An opportunity to start my own career at the best health law program in the

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<http://www.law.uh.edu/healthlaw>

OCTOBER 2002
VOLUME XVI
NUMBER 1



Health Law & Policy Institute UNIVERSITY OF HOUSTON LAW CENTER

Health Law News
is published quarterly by the
Health Law & Policy Institute
University of Houston Law Center
100 Law Center
Houston, TX 77204-6060.
Phone: (713) 743-2101.
<http://www.law.uh.edu/healthlaw>
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Paul Arshagouni

Continued from page 1
country was just too good to pass up.

What are your areas of interest for research?

I am particularly interested in health care policy issues as they relate to children, including access to care and children's rights within the health care system.

How has your impressive combination of degrees affected your legal research?

I suppose that my experiences as a practicing pediatrician and my education in public health have given me an unusual per-

spective on how the health care system affects children and their families. I want to focus my legal research on how we can improve the legal framework to better serve this community.

What do you enjoy doing outside the law?

I enjoy ceramics and have been playing with clay for a couple of years now. Although I have no doubt that I will find opportunities to throw some pots here in Houston, until I do, I will miss the wheel and kiln I left back in Los Angeles. I also enjoy playing a relatively poor game of badminton. I am not a skilled player, but still it is a fun and dynamic game.

New Health Law LL.M. Students Join Program



New Health Law LL.M. students are (from left): Jennifer Jordan, Sandra Foreman, John Lunstroth, Samuel Tilden, James "Jed" Evans, and Harvey Ferguson.

Seven new students have entered the Health Law & Policy Institute's Masters Program.

James W. Evans, Jr. Mr. Evans practices health law with Kroger, Myers & Frisby. He received a B.S. at Texas A&M University in 1993 and a J.D. at the Texas Tech University School of Law in 1996.

Harvey N. Ferguson. Mr. Ferguson has been a trial attorney at the firm of Chaves, Gonzales & Hoblit, L.L.P., which has offices in San Antonio and Corpus Christi, since 1988. He received a B.S. in Pharmacy from the University of Houston in 1982, and he graduated *cum laude* from the South Texas College of Law in 1986.

Sandra K. Foreman. Since January 2001, Ms. Foreman has been Director of Advocacy for Covenant House in Houston, Texas. She received a B.A. in Psychology from the University of Texas in 1992 and a J.D. from the Cleveland-Marshall College of Law at Cleveland State University in Cleveland, Ohio in 1995.

Jennifer K. Jordan. Currently, Ms. Jordan is an attorney with Friend and Associates in Houston, Texas. She received a B.A. at Oklahoma State University in 1993 and a

J.D. at the University of Oklahoma College of Law in 2000.

John Lunstroth. Prior to joining the LL.M. program, Mr. Lunstroth practiced law in a variety of areas, including commercial, exempt organizations, corporate, real estate, and conflict management. He is president of the Texas Society of Homeopathy. He earned a B.A. at the University of St. Thomas in 1977 and a J.D. at the University of Houston Law Center in 1981.

Samuel J. Tilden. Mr. Tilden is a Professor of Pediatrics and Research Compliance Officer at the University of Alabama at Birmingham. He received his B.S. at Tulane University in 1971, his M.S. at University of California at Berkeley in 1973, his M.D. at Tulane University in 1977, and his J.D. at the Birmingham School of Law in 1999.

Marshall L. Wilde. Since 1998, Mr. Wilde has served as a Captain in the Department of the Judge Advocate General of the United States Air Force at Elmendorf Air Force Base in Alaska and Lackland Air Force Base in Texas. He earned his B.A. at the University of Maryland - College Park in 1994. He graduated from the University of Oregon School of Law in 1997.



A Narrow ADA – Unless Congress Repairs It

BY DAVID R. DOW
PROFESSOR OF LAW
UNIVERSITY OF HOUSTON LAW CENTER

For a Supreme Court Justice, Sandra Day O'Connor has been unusually loquacious over the past year. On election night last November, she reportedly expressed distress at the prospect of an Al Gore presidency. More recently, she opined that it appears certain that innocent men have been executed in the United States since the death penalty was reinstated. And in a speech at Georgetown University Law Center last spring, she criticized the Americans with Disabilities Act (ADA) as ambiguous and poorly drafted.

One of the consequences that results when Congress enacts a statute that Supreme Court Justices regard as unclear or ambiguous is that it permits the Court to be less than perfectly faithful to Congress's broad aspirations. In the context of the ADA, this consequence has meant that the Court generally construes the ADA so as to favor corporate employers, at the expense of disabled employees. As the following articles attest, this tendency was starkly manifest in the Court's October 2001 Term.

This past Term, the Court decided four major ADA cases. The resolution of each case disappointed advocates who urge that the ADA be construed liberally and robustly to accomplish its objective of protecting disabled workers. But in construing the ADA in this pro-employer manner, the Court did not break new ground. Indeed, the only surprising thing about the Court's resolution of ADA cases this Term was how undivided the Court was.

In *Toyota Motors v. Williams*, the court gave a narrow reading to the ADA's coverage of employees who develop carpal tunnel syndrome. The opinion for the Court, written by Justice O'Connor, was unanimous. Similarly, the Court's decision in *Chevron v. Echazabal* — which upheld an EEOC regulation authorizing employers to reject job applicants who have medical conditions that may be exacerbated by workplace conditions — was unanimous, with all members of the Court joining Justice Souter's opinion. Even in *Barnes v. Gorman*, which held that municipalities are not liable to private plaintiffs for punitive damages in actions arising under the ADA, the Court's judgment was unanimous, though Justices Stevens, Ginsburg, and Breyer did not join Justice Scalia's majority opinion.

Only in *USAir v. Barnett*, in which the Court made it difficult for ADA protections of disabled workers to prevail when they conflict with other workers' seniority rights, was the Court closely divided, with Justice Breyer writing for a five-justice majority and Justice Scalia (joined by Justice Thomas) and Justice Souter (joined by Justice Ginsburg) in dissent. As the lineups in all these cases make clear, the ADA is not a statute that has riven the Court along traditional ideological

lines; it is rather a statute that the Court has found relatively easy to construe narrowly.

Whether these decisions are individually defensible or sound is, of course, debatable. What is unmistakable clear, however, is that the Court's pattern of ruling for employers this Term and in previous years has created a climate in the lower courts that is inhospitable to disabled workers. Thus, one study indicates that of all the cases decided under Title I of the ADA in 2001, employers prevailed nearly 96 percent of the time. The principal reason for this disparity is that the Supreme Court has construed the term "disability" quite narrowly. But as the recent decisions indicate, the trend has also been cemented by the willingness of the Court to protect seniority benefits of union workers, and by the Court's continued practice of insulating state and local governments from damages liability under federal law.

The Court was more divided in two important non-ADA health-related cases. In *Thompson v. Western States Medical Center*, the Court examined the constitutionality of a provision in the Food and Drug Act that exempts so-called "compound" drugs from certain testing requirements as long as the makers of those drugs refrain from advertising or promoting them. By a five-to-four vote, the Court held that this restriction amounted to an interference with commercial speech, in violation of the first amendment. In an opinion written by Justice O'Connor, the Court rejected the government's argument that the method it had adopted for dealing with compound drugs best protected public health. The case produced an unusual line-up, with Chief Justice Rehnquist, along with Justices Stevens and Ginsburg, joining Justice Breyer's dissent, which would have deferred to the FDA's balancing of the public and private interests at stake.

The Court was also closely divided in *Rush Prudential v. Moran*, albeit along more familiar ideological lines. The question was whether an Illinois law that permitted HMO participants to obtain independent medical review of decisions denying them certain coverage was preempted by ERISA. In another five-to-four decision, with Justice Souter writing for the majority and Justice Thomas writing a dissent (joined by Chief Justice Rehnquist and Justices Scalia and Kennedy), the Court held that because the Illinois law amounted to an insurance regulation and did not intrude upon ERISA's remedial scheme, it was not preempted.

In her speech at Georgetown, Justice O'Connor suggested that the Court's 2001 Term might be remembered as the disabilities act term. If that is true, the Term will also be remembered as the one in which the Court finally cemented its narrow construction of the statute and signaled that if the ADA is going to have new life breathed into it, it will have to be by way of congressional amendment. In the non-ADA cases, consumer interests won one and lost one, but in the ADA cases, this Term was another successful one for the business interests.





Toyota Motor Manufacturing v. Williams Narrowing the Definition of Disability

BY MARY CROSSLEY
PROFESSOR OF LAW
FLORIDA STATE UNIVERSITY COLLEGE OF LAW

In *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 120 S. Ct. 681 (2002), the Supreme Court considered whether a plaintiff with carpal tunnel syndrome has a disability for purposes of the Americans with Disabilities Act (ADA). Although this case was filed under the employment provisions of the ADA, its significance for health lawyers lies in the unanimous Court's articulation of its evolving understanding of who can claim any of the ADA's protections. In *Toyota* the Court announced an explicitly strict standard for evaluating assertions of disability status under the ADA.

Ella Williams worked at a Toyota car manufacturing plant on an engine fabrication assembly line until she was diagnosed with carpal tunnel syndrome and tendinitis, which resulted in her physician's placing permanent restrictions on Williams' engaging in lifting, overhead work, and repetitive use of her elbows and wrists. Over the next five years, Williams' work history at Toyota included assignments to a variety of modified duty jobs and two lawsuits that eventually settled. Relations between the parties finally broke down when a new job assignment caused Williams renewed medical problems, and Williams sued Toyota under Title I of the ADA for failing to reasonably accommodate her disability. The district court granted summary judgment for Toyota on the ground that Williams was not disabled, as defined by the ADA, because her physical impairments did not substantially limit her ability to engage in the major life activities of performing manual tasks, lifting, or working. The Sixth Circuit reversed and granted partial summary judgment to Williams on the issue of whether she was disabled because it concluded that she had been substantially limited in performing manual tasks.

The Supreme Court granted certiorari on the sole question of how the ADA's definition of disability should be applied to an ADA plaintiff who claims to be substantially limited in the major life activity of performing manual tasks. In reviewing the ADA's definition of disability and regulatory explanations of that definition, Justice O'Connor began by emphasizing that the statutory phrase "major life activity" must be understood to refer to "those activities that are of central importance to daily life." Thus, for performing manual tasks to be deemed a major life activity, the manual tasks considered must, taken together, be central to daily life.

The Court went on to announce a stringent standard for deciding when an individual's impairment should be deemed to substantially limit a major life activity and thus rise to the level of a disability. Rejecting the proposition that Congress intended a finding of disability every time a person's impairment "precluded the performance of some isolated, unimportant, or particularly difficult manual task," the Court instead found that an impairment (to be considered

disabling) must prevent or severely restrict the individual from performing a major life activity. In addition the impairment's impact must be permanent or long term. Accordingly, the Court stated that a plaintiff could not prove disabled status simply by providing evidence of a medical diagnosis of an impairment, particularly in the case of a condition (like carpal tunnel syndrome) with respect to which the nature and severity of symptoms vary widely among persons with the condition. Instead, the impact of the impairment must be assessed on a case-by-case basis.

In light of these standards, the Court rejected the Sixth Circuit's analysis, which inquired whether Williams could perform a "class" of manual activities required by her job and failed to ask whether she could perform a variety of manual tasks central to most people's daily lives. The Court of Appeals' focus on the impact of Williams' impairment on her ability to perform workplace tasks was misguided because the manual tasks unique to her (or any other) particular job were not necessarily tasks that are important parts of most people's daily lives. Moreover, while the appellate court had placed great weight on Williams' inability to perform the manual tasks required by her specialized assembly line job, it had disregarded evidence tending to show that she remained able to perform household chores and personal hygiene routines. In concluding that the Sixth Circuit's grant of partial summary judgment to Williams on the question of disability status should be reversed, the Court emphasized that because "household chores, bathing, and brushing one's teeth are among the types of manual tasks of central importance to people's daily lives," the plaintiff's ability to perform these activities should have been assessed in determining if she was substantially limited in performing manual tasks.

Strictly read, the Court's holding in *Toyota* is a limited one: It simply reversed the lower court's grant of summary judgment for Williams and remanded for further consideration of the disability question. In addition, the Court's holding is limited to the proper standard for assessing when the major life activity of performing manual tasks is substantially limited; the Court expressly refrained from addressing whether Williams had presented sufficient evidence to show that her impairment had substantially limited two other major life activities (lifting and working), which Williams had alleged as alternative bases for a finding of disability. (The Court, however, did reiterate its doubts — first expressed in *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) — regarding the conceptual soundness of working as a major life activity.)

The Court's tone and reasoning in *Toyota*, however, have broad implications for future judicial assessments of disability status. Commentators have characterized *Toyota* as a further narrowing of the definition of disability and a continuation of the trend set by *Sutton*, which held that an assessment of an impairment's impact must take into account the effect of any corrective or mitigating measures employed by the individual.

Continued on page 13





Rush Prudential HMO v. Moran The Need for a Consistent Theory of ERISA Health Care Regulation

BY PETER J. HAMMER
ASSISTANT PROFESSOR OF LAW
UNIVERSITY OF MICHIGAN LAW SCHOOL

Rush Prudential HMO v. Moran, 122 S. Ct. 2151 (2002), represents the second time in three years the Supreme Court has decided a case at the contested interface between modern managed care and the Employee Retirement Income Security Act of 1974 (ERISA). For those in search of a holding, *Rush* held that an Illinois statute requiring independent external review of disputed HMO determinations of medical necessity was not preempted by ERISA, because the state law regulated the business of insurance under ERISA's savings clause, and did not afford additional remedies in a manner inconsistent with ERISA's exclusive enforcement provisions. For those interested in understanding the shifting role ERISA plays in determining health policy, however, the lessons are less clear. *Rush* illustrates the role ERISA plays as an implicit form of judicial regulation of health care, betrays the lack of coherence ERISA possesses as a vehicle of health care regulation, and demonstrates the need for a clearer regulatory vision to guide law and policy in this area.

Rush is just the latest opinion to illustrate a much broader trend. Judicial health care regulation via ERISA has undergone a dramatic transformation in the past decade. The significance of these changes is often difficult to calibrate because ERISA operates far below the water line of health policy and the Court is more than a little coy about its intentions. The overall tendency, however, has been the systematic decaying of the original ERISA tiger.

Early ERISA decisions suggested a strong presumption in favor of federal preemption, predicated upon a fairly rote reading of the statute. In contrast, the approach embodied in *Rush* reflects a presumption against federal preemption in areas of historic state police powers, such as health care, in the absence of a clearly manifested congressional purpose. 122 S. Ct. 2159. Early ERISA cases also reflected a narrow reading of the statute's "savings clause" and a restrictive interpretation of what constituted state regulation of the business of insurance. *Rush* adopts a less rigid, "common sense" approach to these issues, 122 S. Ct. 2159, using the antitrust McCarran-Ferguson factors only as guideposts. In practice, *Rush* jettisoned the requirement that the business of insurance embody a "risk spreading" component, 122 S. Ct. 2163-64, meaning that many aspects of regulating the health care dimensions of managed care could potentially be brought within the domain of the savings clause. Finally, early ERISA decisions stingily interpreted ERISA's remedies in a manner that made it difficult for beneficiaries to recover an already limited set of possible benefits. Elaborate exhaustion requirements were imposed before judicial relief could be sought, and plan decisions

were afforded substantial deference. *Rush* reflects a very different temperament. *Rush* starts with a skeptical attitude towards plan decisions, recognizing the inherent conflict of interest underlying managed care. 122 S. Ct. 2169 n.15. As such, the Court suggests that plan administrators are not entitled to special deference. Moreover, *Rush* opens the door for states to add various procedural requirements to the plan's dispute resolution process under the guise of regulating the business of insurance, even permitting, as was the case with *Ms. Moran*, a beneficiary to obtain relief outside of the plan's own terms.

How could such dramatic changes take place in such a relatively short period of time? The sheer elasticity of plausible statutory interpretations illustrates how under-determined the ERISA legislation is. Given this indeterminacy and the patchwork manner of judicial decision making, there is a need to articulate a clearer policy vision to guide ERISA lawyers and judges as they continue to act as health care regulators. This requires expressly developing and choosing between competing theories of health care regulation, not unlike debates that commonly take place in fields like environmental law. Two issues are particularly important. There is a need to reexamine the federal interest underlying ERISA as it is applied to health care. Relatedly, there is a need to more consciously define the boundary between tort law and contract law in employer-provided managed care plans.

Uniformity is the interest traditionally asserted to justify federal ERISA preemption. Employers often operate in many different states. Uniform procedures and remedies supposedly decrease the costs of providing health care benefits, and therefore increase the likelihood that such benefits will be offered. Ironically, however, ERISA has been interpreted to permit states to substantively regulate the types of benefits that plans must provide, even as its exclusive remedy provisions were treated as sacrosanct. This may be the exact wrong approach. An alternative vision would redefine the federal interest in terms of employer autonomy, rather than uniformity, emphasizing employer freedom in plan design. In this regime, state laws would be preempted if they unduly interfered with employer autonomy. At the same time, states (or the federal government) could be extended a freer hand to

regulate the process in which plans were administered to provide more meaningful standards of accountability. State rules could more aggressively enforce fiduciary duties, mandate information disclosure, and police forms of opportunistic behavior by plan providers.

A redefined federal interest in terms of employer autonomy would give clearer preemptive weight to a contractarian philosophy of health care regulation. Underlying the *Rush* opinion are numerous paradigmatic conflicts. There are tensions between theories of tort and contract, between market and professional paradigms, and between status-based and choice-

Continued on page 13





The Supreme Court and Disability Law, 2002

BY SAMUEL MARCOSSON
LOUIS D. BRANDEIS SCHOOL OF LAW
UNIVERSITY OF LOUISVILLE

Supreme Court pundits are always looking for themes to explain the Court's work in a particular Term – 1988-89 was the "employment discrimination Term," for example. In that tradition, the Term that ended in June 2002 must inevitably be coined the "ADA Term," for the Court did an extraordinary amount of work interpreting the Americans With Disabilities Act. Elsewhere in this edition of Health Law News, Professor Mary Crossley has written in detail about the Court's important decision in *Toyota Motor Mfg. of Kentucky v. Williams*, so I will focus primarily on two other decisions: *U.S. Airways, Inc. v. Barnett*, 122 S. Ct. 1516 (2002), and *Chevron U.S.A. Inc. v. Echazabal*, 122 S. Ct. 2045 (2002). What is interesting about these two cases (and *Williams* as well, as I will briefly explain at the end of this article) are the degree to which statutory language took a back seat as the Court reached and explained its conclusions, and the consistency of the Court's course in narrowing the ADA's protections.

Barnett dealt with the scope and limits of the ADA's requirement that employers provide "reasonable accommodations" for the disabilities of their workers and applicants. The specific issue was whether an employer could interpose the existence of a seniority system as an a priori limitation on the extent of its obligation to accommodate an employee. The most common situation raising this issue was the one actually involved in *Barnett*: the employee asks for an accommodation involving a transfer or assignment to another position in which his or her disability would not be an impediment to performance. U.S. Airways asked the Court to permit it to deny the request if it maintained a seniority system which would entitle another employee to that position.

The Court took a middle-ground position in *Barnett*. It rejected U.S. Airways' almost incomprehensible position that an accommodation request is not reasonable if it "grants the employee with a disability treatment that other workers could not receive." As Justice Breyer's opinion for the Court pointed out, "[T]his argument fails to recognize what the Act specifies, namely, that preferences will sometimes prove necessary to achieve the Act's basic equal opportunity goal. . . . By definition any special 'accommodation' requires the employer to treat an employee with a disability differently, i.e., preferentially." *Barnett*, 122 S. Ct. at 1521.

So in rejecting U.S. Airways' extreme position, what did the Court offer in its place? The Court could, of course, have examined the statute to determine what limits Congress placed on the employer's burden to accommodate. Such an examination would have yielded a clear expression of Congress's view: the burden ends where "undue hardship" begins. As the statute itself says, discrimination includes:

"not making reasonable accommodations to the known physical or mental limitations of an otherwise qualified employee with a disability . . . unless such covered entity can demonstrate

that an accommodation would impose an undue hardship on the operation of the business . . ."

42 U.S.C. § 12112(b)(5)(A) (emphasis added). The most obvious statutory approach, then, would have asked whether departing from a seniority system constitutes an undue hardship. As the statute makes clear, the employer bears the burden of proof on the undue hardship issue.

Instead of interpreting the ADA in the way most consistent with the language, however, the Court rendered the inquiry into hardship (and the employer's burden of proof) irrelevant. It crafted a general rule that any accommodation request that would violate existing seniority systems "ordinarily" is not reasonable, without reference to any hardship it may or may not create for the employer. Even in a situation where granting the request would involve no hardship whatsoever for the employer, the employee seeking the accommodation will still face a strong presumption that the seniority system trumps the ADA right, and must bear the "burden of showing special circumstances that make an exception from the seniority system reasonable in the particular case." *Barnett*, 122 S. Ct. at 1525.

That is not to say hardship is now irrelevant. As a practical matter, one "special circumstance" to which an employee might point would be the apparent lack of any hardship. This means, however, that the Court has moved the inquiry regarding hardship from its statutory perch as a separate and distinct step in the analysis and made it a mere part of determining whether the accommodation is reasonable. At first glance, this might seem little more than semantics, but there is that sticky issue of the burden of proof. Under the most employer-friendly reading of *Barnett*, an employee may lose even if the employer would incur no hardship whatsoever. At best, the lack of hardship might be relevant, but not in the way or to the degree the statute contemplated.

The deference the Court gave to seniority systems in *Barnett* also ignored one other aspect of the ADA. When it passed the Civil Rights Act of 1964, Congress included a specific provision protecting seniority systems from the full coverage of Title VII as it applies to other employment practices. 42 U.S.C. § 2000e-2(h). The Court has relied in this provision in at least two cases to protect seniority systems from discrimination challenges brought under Title VII. See *Trans World Airlines, Inc. v. Hardison*, 432 U.S. 63, 81-82 (1977); *Teamsters v. United States*, 431 U.S. 324, 352-53 (1977). The ADA, however, contains no such special protection for seniority systems. As Justice Souter pointed out in *Barnett*:

"Because Congress modeled several of the ADA's provisions on Title VII, its failure to replicate Title VII's exemption for seniority systems leaves the statute ambiguous, albeit with more than a hint that seniority rules do not inevitably carry the day."

Barnett, 122 S. Ct. at 1533 (Souter, J., dissenting). The Court ignored the absence of language in the ADA protecting seniority systems. Continued on page 13





Compounding a Constitutional Error? Pharmaceuticals and Free Speech

BY LARS NOAH
RESEARCH FOUNDATION PROFESSOR
UNIVERSITY OF FLORIDA COLLEGE OF LAW

In *Thompson v. Western States Medical Center*, 122 S. Ct. 1497 (2002), the Supreme Court invalidated a provision of the Food and Drug Administration Modernization Act of 1997 (FDAMA), which had authorized pharmacists to engage in the extemporaneous compounding of pharmaceutical products without securing separate approvals from the FDA, but which prohibited pharmacists from advertising the fact that they compounded particular types of drugs. A bare majority of the Court held that the latter restriction ran afoul of the First Amendment. Curiously, the pharmacists who had brought the challenge chose not to cross-petition for review of the lower court's decision that the unconstitutional advertising restriction was not severable from the remainder of FDAMA's compounding provisions. As a result, they may have won the battle but lost the war insofar as pharmacists who compound drugs now again face closer FDA regulation of their activities.

As it happens, the Supreme Court initially had extended First Amendment protections to "commercial speech" a quarter of a century ago in a case striking down a state prohibition on pharmacy advertising of prescription drug prices. As an exercise in constitutional jurisprudence, *Western States* hardly breaks new ground. The members of the Court evaluated the case using a well-worn form of intermediate scrutiny, differing in their respective assessments of whether the government had demonstrated a sufficient nexus between the means selected and its asserted interest in preventing the risks associated with the commercialization of unapproved new drugs under the guise of pharmacy compounding. The decision does stand out as the first time that the Supreme Court has invalidated a recently enacted congressional restriction on advertising, thereby showing little deference to the judgments of a coordinate branch of government, and it certainly solidifies a trend evident over the last decade of taking seriously the constitutional rights of entities wishing to engage in commercial speech.

There are, of course, several important subtleties to the Court's analysis. Justice O'Connor's opinion for the majority offered a somewhat cramped reading of the government's asserted interest—as simply wanting to draw a line between large-scale drug manufacturing and small-scale pharmacy compounding—and then rejected the government's argument that the act of advertising the availability of particular drugs served as a proxy for commercial activity that should have to comply with the FDA's premarket approval requirements. Justice O'Connor suggested a number of other alternatives for making such a distinction without needing to restrict speech.

The majority's unforgiving application of the nexus requirement approaches the least restrictive means test normally reserved for strict scrutiny cases and demands a probably unattainable level of legislative

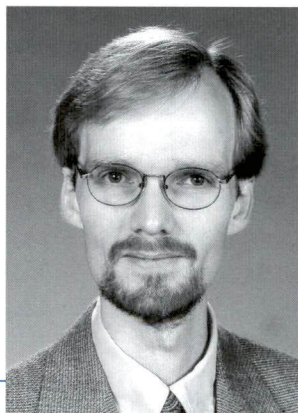
precision. It also fails to concede that Congress had not in fact prevented pharmacists from advertising the fact that they offered compounding services in general or that they offered particular types of drugs—it simply insisted that, before doing the latter, pharmacists satisfy the FDA's demanding new drug approval requirements or face the risk of sanctions identical to those applicable to other entities that might attempt to sell unapproved new drugs. Justice Breyer's opinion for the dissent imagined a more expansive governmental interest in dampening the demand for unneeded and potentially dangerous pharmaceuticals, and he then crafted an argument that apparently would allow the agency to completely prohibit the advertising of any prescription drugs directly to consumers. The majority appropriately rejected this line of argument.

In some ways, the FDA's reaction to the Court's fairly narrow decision represents the most startling aspect of this litigation. Instead of a grudging response, the agency appears to have taken the occasion to reconsider its entire approach to regulating medical technologies and other products. Traditionally, the FDA has depended on its ability to control product information. Less than three weeks after the Court announced its decision, the agency published a notice inviting comment on a series of questions that, while carefully framed in neutral terms, implied that it might welcome suggestions favoring the deregulation of labeling and advertising. See 67 Fed. Reg. 34,942 (2002). It took another three weeks before the FDA responded to the Court's more limited holding by issuing a revised guidance document to govern pharmacy compounding. See 67 Fed. Reg. 39,409 (2002). The agency almost never moves with such dispatch.

Does this trial balloon portend a relaxation of existing FDA restrictions on the labeling and advertising of prescription drugs and medical devices, whether the promotional messages are directed to health care professionals or consumers? If understood as mechanisms for dampening inappropriate demand, perhaps they would not survive constitutional scrutiny. For instance, the longstanding prohibition against advertising Schedule II controlled substances directly to consumers may fail under the Court's robust test for commercial speech. If, however, the existing restrictions represent efforts to reduce the transmission of potentially misleading information, nothing in the Court's increasingly protective approach to commercial speech would seem to stand in the way of continued regulatory oversight. See Lars Noah, *Medicine's Epistemology: Mapping the Haphazard Diffusion of Knowledge in the Biomedical Community*, 44 ARIZ. L. REV. 373 (2002).

The FDA's announcement represents a dramatic about-face for an agency that until recently had taken the position that it need not concern itself with the First Amendment. See Lars Noah, *What's Wrong with "Constitutionalizing Food and Drug Law?"*, 75 TUL. L. REV. 137 (2000). Although an admirable act of self-examination, the announcement also reveals a significant shift in personnel at the agency: the new Chief Counsel had spent a number of years representing the Washington

Continued on page 14



FROM THE WEB

The articles below appeared in *Health Law Perspectives on the Health Law & Policy Institute's Web site* at <http://www.law.uh.edu/healthlawperspectives> between June 27 and August 30, 2002.

- Phyllis Griffin Epps, We Live, We Learn
- Jill S. Hueter, Nutrition in Schools
- Phyllis Griffin Epps, Let Them Eat Cake
- Ronald L. Scott, Legal Liability and the Occupational Physician
- Melanie R. Margolis, Supreme Court Term Rough for ADA: *U.S. Airways v. Barnett*
- Melanie R. Margolis, FDA May Not Prevent Pharmacists from Promoting Compounded Drugs
- Melanie R. Margolis, Governor Orders Policy Changes to Encourage Community-Based Alternatives for Persons with Disabilities
- Ronald L. Scott, Men's Health: Osteoporosis
- Melanie R. Margolis, ACIP Releases Updated Smallpox Vaccination Strategy: Some Experts Disagree with Policy
- Ronald L. Scott, Texas May Increase Cigarette Excise Tax Rate
- Melanie Rubinsky, Ohio Supreme Court Expands the Physician-Patient Relationship
- Sandra L. Burr, Fortune Favors the Brave: The Continuing Story of Lorenzo's Oil
- Alice M. Maples, Questions Raised by John Q
- Joseph J. Wang, Tax Incentives for Physicians Providing Charity Care
- Mark Martyn, Baby Boomers' Impact on Nursing Homes
- Laura Hermer, Trish74 and the Regulation of Surrogacy Contracts
- Michael S. Ewer, M.D., Fraudulent Access to Entitlement Programs: Is the Time Ripe for Legislative Intervention?
- Ronald L. Scott, E-Prescribing
- Melanie R. Margolis, What is Causing the Dramatic Rise in Medical Malpractice Insurance Rates in Texas

This article first appeared in *Health Law Perspectives on the Health Law & Policy Institute Web site* at <http://www.law.uh.edu/healthlawperspectives> on August 30, 2002.

NUTRITION IN SCHOOLS

By Jill S. Hueter, J.D. Candidate

On April 22, 2002, the Texas Education Agency issued a new policy regarding the sale of foods of minimal nutritional value (FMNV) in schools to be implemented for the start of the 2002-03 school year. The policy is a response to a January 16, 2001 United States Department of Agriculture (USDA) memorandum, which clarified existing regulations on competitive foods. Competitive foods are foods sold outside of the school meal program. Prior to the USDA memorandum, many Texas schools had banned vending machines from the cafeteria but allowed them in other eating areas.

The new policy defines the terms food service area and meal period. FMNV may not be available in any area in which reimbursable meals are either served and/or eaten, including areas outside the traditional cafeteria such as courtyards, hallways, and classrooms. Meal periods include both the time of serving and the time allotted to students for eating their meals. The idea behind the policy is to encourage students to eat healthier meals

and to reduce childhood obesity. Schools that fail to comply may lose their school lunch subsidies for all meals served on the day of the violation.

The USDA has established four categories of FMNV: soft drinks, water ices, chewing gum, and certain candies (e.g., hard candy, jellies and gums, marshmallow

State agencies and local school food authorities are authorized to impose additional restrictions on the sale of competitive foods.

candies, licorice, and candy-coated popcorn). These foods provide less than 5% of the recommended dietary allowance for key nutrients. Most chocolate bars, potato chips, and ice cream still make the cut under regulations set forth by the USDA. The policy does not address vending machines and does not require that schools remove vending machines. It requires that during meal periods, vending machines stocked with FMNV must be

unplugged or locked, restocked with items not prohibited or placed in areas where food is neither served nor eaten.

The federal law is implemented in Section 210.11 of the National School Lunch Program (NSLP) regulations and Section 220.12 of the School Breakfast Program (SBP) regulations. At a minimum, these rules or regulations must prohibit the sale of FMNV in the food service areas during meal periods. State agencies and local school food authorities are authorized to impose additional restrictions on the sale of competitive foods.

Background

Texas was the nation's 14th most obese state in a United States Centers for Disease Control and Prevention (CDC) study published in the May 22, 2002 *Journal of the American Medical Association*. A 1999-2000 pilot study in Austin found 9% of kindergarteners, 23% of first-graders, and 23% of second-graders were obese based on body mass index (BMI) measurements. A 1999 evaluation of El Paso third-graders by the University of Texas at El Paso found

that 35% of boys and 29% of girls were overweight, while 22% of boys and 15% of girls were clinically obese.

Nationally, about 13% of children aged 6-11 are overweight, almost double the percentage 20 years ago, and the percentage for overweight adolescents aged 12-19 has almost tripled, now at 14%, according to the CDC. There are approximately ten million children nationwide who are overweight, which would mean about 800,000 children in Texas.

A CDC study published in the May 2002 journal *Pediatrics* found that costs related to childhood obesity have more than tripled in the past 20 years, reaching \$127 million by 1999. Children are being hospitalized for obesity-related illnesses including diabetes, sleep apnea, gallbladder disease and asthma.

The United States Department of Health and Human Services (HHS) Secretary, Tommy Thompson, released a report on June 20, 2002 stating the total cost of overweight and obesity for children and adults in 2000 to be estimated at \$117 billion. Obese individuals spend approximately 36% more than the general population on health services and 77% more on medications.

One of the most serious aspects of overweight and obesity in children is Type II diabetes. A diabetes specialist at Texas Children's Hospital reported that the number of pediatric patients diagnosed with Type II diabetes rose from less than 5%, before 1995, to 31% last year. Type II diabetes is a metabolic disorder resulting from the body's inability to either make enough insulin or properly use it. It can result in several life-threatening complications, including blindness, kidney disease, nerve disease, lower-extremity amputations, heart disease and stroke.⁹ According to the CDC, diabetes is the seventh leading cause of death in the United States.

Poor diet is one cause for the increase in childhood obesity. A January 2001 report to Congress entitled *Foods Sold in Competition with USDA School Meal Programs* found that only 2% of school-aged children meet the Food Guide Pyramid serving recommendations for all five major food groups. Children often replace school meals with less nutritious foods and beverages, causing an inadequate daily intake of key nutrients necessary for growth and learning. When competitive foods are purchased in

addition to school meals or in large quantities, there is the likelihood of over-consumption and weight gain.

One popular category of FMNV is soft drinks, which can be found in vending machines throughout many schools. In a study published in the February 17, 2001 edition of the British medical journal the *Lancet*, Boston researchers discovered that each additional serving of soda per day increases the risk of obesity by about 60% in children. The National Soft Drink Association (NSDA) refutes the claim pointing to research by the Georgetown University Center for Food and Nutrition Policy and Michigan State University that shows no relationship between soda consumption by children and obesity. The NSDA says a ban on sodas is not necessary to combat childhood obesity, instead

Children often replace school meals with less nutritious foods and beverages, causing an inadequate daily intake of key nutrients necessary for growth and learning.

promoting increased physical activity and nutrition education.

For many schools, beverage marketing contracts and pouring rights with soft drink companies are a common source of additional income. Many of these contracts have provisions that increase the percentage of profits schools receive when sales volume increases. This is a substantial incentive for schools to promote soft drink consumption by adding vending machines, as well as increasing the times they are available. Sixty-nine percent of secondary schools obtain additional funds through partnerships with food and beverage companies. Houston Independent School District estimates it receives \$2 million in revenue from vending machine sales annually. Administrators say the loss of proceeds from vending machine sales could hurt student activity funds.

Other States

Nineteen states, three territories, and the District of Columbia have passed laws stricter than USDA regulations. States with restrictive competitive food policies, like Louisiana, West Virginia, Georgia, and Mississippi, maintain rates of participation

in school meal programs that are higher than the national average.

In some states (e.g., Colorado, Connecticut, Idaho, and Nebraska), competitive food sales are not allowed from one half-hour before until one half-hour after the breakfast/lunch period. The District of Columbia, Kentucky, Maryland, and New York prohibit competitive foods on campus from the beginning of the school day until after the last lunch period. In other states (e.g., Illinois, Louisiana, New Jersey, North Carolina, and Virginia), the income from competitive food sales must accrue to the school food service. In the state of Maine, the sale of competitive foods is prohibited on campus at all times.

The West Virginia Board of Education prohibits the sale of chewing gum, candy bars, food or drinks containing 40% or more sugar or other sweeteners, juice or juice products containing less than 20% real fruit or vegetable juice, and foods with more than eight grams of fat per ounce serving. Soft drinks are prohibited at all times in elementary and middle schools and during breakfast and lunch periods in high schools.

In California, the sale of all foods outside the school meal program during the school day has been eliminated in elementary schools. Competitive foods served in California secondary schools must meet strict fat, sugar, and portion size guidelines. Beverages allowed on campuses include water, low-fat and nonfat milk, and drinks that contain at least 50% fruit juice with no added sweeteners. Snacks and side dishes must have no more than 30% of calories from fat, no more than 10% of calories from saturated fat, and no more than 35% added sugar by weight to be allowed in schools. Large or oversized portions for these snacks as well as entrée items are prohibited.

Federal Legislation

On July 30, 2002, U.S. Senators Bill Frist, Jeff Bingaman and Christopher Dodd introduced legislation aimed at reducing obesity among children. The Improved Nutrition and Physical Activity Act or IMPACT focuses on health education and research to reduce the problem. The legislation proposes spending as much as over \$200 million next year and additional money in future years on a variety of programs to encourage better nutrition, physical activity, and further research on obesity.

Institute Meets with Visiting Korean Law Professor

On July 15, 2002, faculty from the Health Law & Policy Institute met with Dr. Kyu-Yong Park from South Korea. Dr. Park, a Professor of Law at Silla University in Pusan, traveled to Houston under the auspices of the U.S. Department of State's International Visitor Program. The Korean government is strongly considering a proposal to move toward a case study-centered system like that which is used in American law schools, and the law school at Silla University has been a leader in this movement and has already made changes to implement the new method of teaching. Dr. Park has been a leader in this reform movement, and he came to the U.S. to gain first-hand knowledge about U.S. legal education system including curriculum and organizational structure.

While in Houston, Dr. Park met with Institute faculty to learn about the health law program and discuss cutting edge U.S. health law issues. Also, Dr. Park visited the Veterans Administration Hospital where three students from the University of Houston Law Center are participating in the Health Law Clinic, including Sung Soo Choi, A University of Houston Law Center LL.M. student from South Korea,



Ronald Scott, Phyllis Griffin Epps, Mary Anne Bobinski, Dr. Kyu-Yong Park, Barbara Williams, translator Hyon Lee Green, and Melanie Margolis

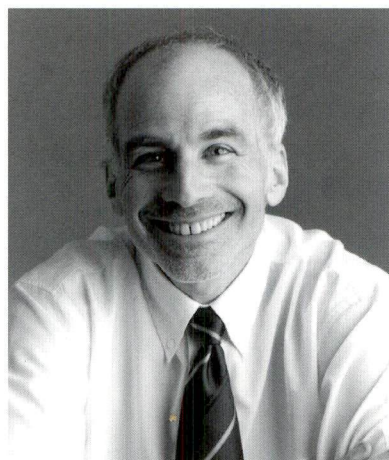
who spoke with Dr. Park about his experiences at the law school and the Health Law Clinic. Dr. Park met with Professor Jordan Paust about the University of Houston's international program.

Dr. Park received his Doctorate of Jurisprudence from Trier University in Germany and has lectured at a number of law schools in East Asia. He has published on various topics including Impossibility of Performance, Contract Cancellation,

Product Liability Law, and Legislation of German Civil Law. The South Korean legal system is based on the German model, as inherited from the Japanese. South Korean legal education is also based on the European model, focusing on theory rather than practice.

You can learn more about the International Visitor Program by visiting the U.S. State Department's website at <http://exchanges.state.gov/education/ivp/>.

Gostin Will Teach Institute's 2004 Intersession Course



Lawrence O. Gostin

The Health Law & Policy Institute sponsors a January Intersession course taught by a leading health law scholar each year. The Institute is pleased to announce that Lawrence O. Gostin, internationally recognized scholar in law and pub-

lic health, will teach Advanced Public Health Law & Ethics at the University of Houston Law Center in January 2004.

Gostin is Professor of Law at Georgetown University, Professor of Public Health at the Johns Hopkins University, and the Director of the Center for Law & the Public's Health at Johns Hopkins and Georgetown Universities. He is also the Co-Director of the Georgetown/Johns Hopkins Program on Law and Public Health. Professor Gostin has a J.D. from Duke University and an Honorary Doctorate of Law conferred by the Chancellor of the State University of New York (system-wide). Professor Gostin recently returned from a serving as a Visiting Scholar at the Centre for Socio-Legal Studies, Oxford University. Professor Gostin's latest books, *Public Health Law: Power, Duty, Restraint* (2000) and *Public Health Law and Ethics: A Reader* (2002), are both published by the University of California Press and the Milbank Memorial Fund.

Robert M. Toth Presents Second Health Law LL.M. Writing Award

On October 3, 2002, past and current health law masters students gathered in the Health Law & Policy Institute library for a dinner and the presentation of the 2002 Robert S. Toth Health Law LL.M. Writing Award. First presented in 2001, this award honors a health law masters student for his or her outstanding performance in the Health Law LL.M. program. Bill Winslade, Distinguished Visiting Professor of Law and Associate Director for Graduate Programs, introduced Robert S. Toth (LL.M. '93). Mr. Toth announced the winner of the award. The second annual Robert S. Toth Health Law LL.M. Writing Award was presented to Laura Hermer. Ms. Hermer's thesis will be published as *Paradigms Revised: Intersex Children, Bioethics and the Law*, 11 ANN. HEALTH L. _ (2002) (in press).

SPECIAL SECTION

Narrowing the Definition of Disability

Continued from page 4

As in *Sutton*, the Court fixated on 43,000,000 – the number of Americans that Congress estimated, in the ADA's legislative findings, to have disabilities – as support for its adoption of a strict standard that would limit the number of plaintiffs able to prove disability.

Less noted has been *Toyota's* implicit rejection of the reasoning in *Bragdon v. Abbott*, 524 U.S. 624 (1998), in which the Court dismissed the proposition that major life activities should be limited to activities with public, economic, or daily dimensions and held that reproduction is a major life activity for the purposes of the ADA. In stating that the phrase "major life activities" "refers to those activities that are of central importance to daily life" and unanimously declaring that the statutory definition of disability "need[s] to be interpreted strictly to create a demanding standard for qualifying as disabled," the Court in *Toyota* appears to seek to further the enterprise of setting apart for ADA protection the so-called "truly" disabled. While disability rights advocates have criticized the decision as unduly restrictive and inconsistent with the ADA's broad remedial purpose, at this point their only remedy may lie in Congressional action clarifying the definition of disability.

ERISA Health Care Regulation

Continued from page 5

based distinctions. The Illinois statute at issue privileged the insights of physicians as the ultimate decision makers. Moreover, the Court intimated that interpreting the term "medical necessity" necessarily lies in the realm of medical professionalism and not the parties private contractual intent. In the wake of *Rush*, it is interesting to ask whether an employer plan

What is clear is that managed care continues to raise complicated social, economic and legal questions, and that ERISA provides an inadequate forum for their resolution.

could contract for medical benefits in terms other than "medical necessity," or whether it could define "medical necessity" for plan purposes in a manner that conflicted with traditional professional understandings. The five Justices constituting the *Rush* majority might find such a contract provision contrary to its understanding of public policy. Moreover, if a state law clearly mandated that managed care

plans must provide all medically necessary care, it is doubtful that such a law would be preempted under current understandings of ERISA which permit state-mandated benefits.

Depending upon one's broader understandings of health policy, these may or may not be proper outcomes. What is clear is that managed care continues to raise complicated social, economic and legal questions, and that ERISA provides an inadequate forum for their resolution. Ms. Moran received an independent external review of her HMO's treatment determination. It is time that the entire relationship between ERISA and managed care be subjected to similar independent review and subsequent reform.

The Supreme Court and Disability Law, 2002

Continued from page 6

The Court's decision in *Chevron U.S.A., Inc. v. Echazabal*, 122 S. Ct. 2045 (2002), echoes a similar theme in the extent to which the Court seemed to concentrate less on the statutory language than we might expect from the current Justices. There, the Court considered a regulation promulgated by the Equal Employment Opportunity Commission that permits employers to refuse to hire an individual with a disability if he or she poses a "direct threat to the health or safety of the individual or others in the workplace." 29 C.F.R. § 1630.14(b)(2) (2001) (emphasis added). The regulation was controversial because it seems, on its face, contrary to the language of the ADA itself, which permits an employer to impose "a requirement that an individual shall not pose a direct threat to the health or safety of other individuals in the workplace." 42 U.S.C. § 12113(b) (emphasis added).

Chevron refused to hire Mario Echazabal for work at an oil refinery, even though he had worked for an independent contractor at the same facility for over twenty years. *Chevron* based its decision on the belief of its medical staff that continued exposure to toxic substances at the refinery would aggravate damage that had been done to Echazabal's liver by Hepatitis C. Ultimately, *Chevron* prevailed on the contractor to end his exposure to the chemicals, and he was laid off in 1996. Echazabal sued under the ADA, arguing that *Chevron* could not refuse to hire him on the basis of his disability even if his presence in the refinery would present a direct threat to his own health or safety.

In many cases, of course, a job applicant may present a threat to the health or safety of him or herself as well as others on the job. Here, however, since there was no basis for arguing that Echazabal's presence would constitute a threat to others in the workplace, his claim required the Court to consider the validity of the EEOC's regulation extending the statute's "direct threat" provision from "other individuals in the workplace" to "the individual

or others in the workplace."

Despite the apparent contradiction, the Court held unanimously that the regulation was permissible. It concluded that the reference to "other individuals" was merely an example of the sorts of qualifications standards an employer may implement. It thus did not rule out the possibility that the EEOC's regulation could extend to other standards, including the presence of threats to the health or safety of the individual. The ADA requires simply that such standards be "job-related and consistent with business necessity," which the Court felt were "spacious defensive categories, which seem to give an agency ... a good deal of discretion in setting the limits of permissible qualifications standards." *Echazabal*, 122 S. Ct. at 2050.

From a health law perspective, the most intriguing aspect of *Echazabal* may not lie in the wide berth it gave the EEOC in formulating the regulation at issue, but in the fundamental inconsistency between the Court's approach to the problem and its own landmark decision a decade earlier in *International Union, UAW v. Johnson Controls, Inc.*, 499 U.S. 187 (1991). In *Johnson Controls*, the Court rejected an employer's attempt to invoke concern for a workers' health in defense of a policy barring fertile women from

"Decisions about the welfare of future children must be left to the parents who conceive, bear, support, and raise them rather than to the employers who hire those parents."

certain positions (primarily those involving exposure to lead) in its battery-making facility because of the potential impact on their reproductive systems and any children they might later bear. At one level, the decisions can be distinguished because the employer in *Johnson Controls* was required to show its policy passed muster under Title VII's bona fide occupational qualification (BFOQ) defense, rather than "more lenient" business necessity standard, which was at issue in *Echazabal*. Or it can be argued that the decisions are mostly about administrative law principles, since the Court was deferring to the EEOC's regulation in *Echazabal*, whereas the EEOC did not support the employer's position in *Johnson Controls*.

At a deeper level, though, the cases are not so easily distinguished. They reflect widely divergent approaches to the fundamental question of who gets to make crucial decisions when workplace and health needs seem to conflict. The decision in *Johnson Controls* reflected the view that Title VII took away from



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Pharmaceuticals and Free Speech
Legal Foundation in pursuing commercial speech challenges to other FDA policies, and the position of Commissioner has remained vacant for more than a year. Hopefully, Dr. Mark McClellan, who was just appointed to fill the post, will provide some needed leadership on this important issue. Otherwise, the FDA may end up over-reading the Supreme Court's latest constitutional guidance and needlessly stripping itself of essential regulatory tools.

Combined with the Court's pre-2002 ADA jurisprudence, Barnett, Echazabal, and Williams show a general trend towards the ADA, notwithstanding Congress's explicit intent when it passed the law in 1991. It be comprehensive and sweeping in opening doors for individuals with disabilities. While there remains no doubt that the ADA has made an enormous difference in the lives of the people Congress intended to benefit, there must be great (and growing) doubt about whether the Supreme Court is allowing it to have the impact its sponsors hoped for a decade ago.

The ADA says that an individual must be "substantially limited" in one or more "major life activities" in order to be protected by the statute.

skeptical of my claim that the Court's 2002 ADA's actual language. The ADA says that an individual must be "substantially limited" in one or more "major life activities" in order to be protected by the statute. The Court interpreted both of these two crucial phrases in *Williams*, adding more than a little gloss to each when it said: "[T]o be substantially limited

in performing manual tasks, an individual must have an impairment that prevents or severely restricts the individual from doing activities that are of central importance to most people's daily lives." *Williams*, 122 S. Ct. at 691 (emphasis added). I confess to a lack of expertise in linguistics, but the difference between "substantially limited" (the statutory language) and "prevents or severely restricts" (the Court's interpretation) seems obvious, as does the gulf between a "major life activity" and one that is "of central importance to most people's daily lives."

employers the right to act on the basis of a protected classification (in that instance, sex) even if it was doing so not out of invidious bias but for "benign," even laudable reasons. It was, at its core, a strike against employer paternalism; and it permitted the women involved to make their own decisions about how to balance economic and lifestyle needs against medical risks. As the Court put the point, "Decisions about the welfare of future children must be left to the parents who conceive, bear support, and raise them rather than to the employers who hire those parents." But in the case of individuals with disabilities, *Echazabal* retreats from this stance, and seems to accept the idea that an employer should have the authority to balance the risks and the benefits. While it is not that unusual for the Court to shift its perspective over the course of a decade, what is remarkable is that seven Justices, whereas its bookend *Echazabal* was unanimous in the opposite direction. Rarely has the Court moved so far, so fast, and with such unanimity. It is speculative, of course, but it seems more than plausible that the difference between the two cases reflects our society's rejection of sex-based paternalism, but our continuing belief, even in the ADA era, that people with disabilities must be cared for. Finally, let me add a brief note about *Williams*, for those readers who may be

11-2-02

Robert C. McCay
(B.S. '44, M.S.P.E.
'47) ... named

senior vice president of Texaco, Inc., and president of Texaco Europe. McCay will direct all foreign petroleum operations from Texaco's Harrison, New York, offices.



Larry A. Warzel (B.S.P.E. '47) ... appointed manager of the newly established district office of Custom Oil Recovery Technology (CORT) company in Bartlesville.

Virginia Myers (M.F.A. '49) ... participated in a concert sponsored by the East Central Cultural Committee and the Oklahoma Arts Council. Myers is pianist and music director of the Tulsa-based Living Arts Chamber Ensemble, Oklahoma's only professional group specializing in new music.

William S. Jones
(B.S. '51) ...

recently retired from the top civilian position among 16,200 civilians employed at Tinker Air Force Base in Oklahoma. He had been deputy director of material management.



Richard Klabzuba (B.A. '54, M.B.A. '55) ... has become a Democratic candidate for the U.S. Senate. He is a Tulsa native.

Reverend Betty Lou Neel (B.S. '57) ... named pastor of First Presbyterian Church in Wagoner, Oklahoma. She is the city's first full-time woman pastor.

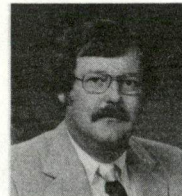
James E. Brazell (J.D. '59) ... named staff director of the

Class Notes



and general manager of American Fertilizer and Chemical Co. of Henderson, Colorado, a subsidiary of Phillips Petroleum Co.

Don M. Patterson (B.S. '65, J.D. '68) ... named administrative vice president for Marion Corporation in Mobile, Alabama.



R. Bruce Dains (M.M. '66) ... has become an architect/project manager for the U.S. Army Corps of Engineers in Washington, D.C. He is married to the former Beverly Kleinmann (B.S. '68).

Cliff Stewart (B.A. '66) ... appointed manager of Natural Gas Liquids Operations in Enterprise Products Co.'s Denver, Colorado office.

Communication, Inc. Roberts received the award for her many newsworthy community contributions. She is the founder and producing director of Tulsa's American Theatre Company.

Jackson L. Bowden
(M.B.A. '69) ...

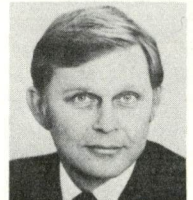
promoted to assistant comptroller at American National Bank and Trust Company in Chicago.



State Rep. Don McCorkell Jr. (B.A. '69, J.D. '73) ... spoke on "The Neglected Aged" at the second annual Seminar on Aging at Cameron University. McCorkell is chairman of the Oklahoma Legislature's Special Committee on Aging.

Ruthe Blalock Jones (M.A. '72) ... served as a juror for the Five Civilized Tribes Student Art Show in Muskogee, Oklahoma.

J. Keith McSorley (B.S.P.E. '72) ... promoted to division supervising engineer with the Midcontinent Production Division of Exxon Company U.S.A. in Midland, Texas.



Mike Cody (B.S. '73) ... named assistant deputy director in charge of probation and parole for the Oklahoma Department of Corrections.

Donald B. Dahlin (B.S. '73) ... named second vice president of the Group Division at Massachusetts Mutual Life Insurance Company of Springfield.

Tish Peitz, (B.S. '73) ... associate director of admissions ... has been elected president of the Great Plains Association of College Admissions Counselors.



Lance Henson (M.A. '74) ... recently taught a poetry workshop at the Oklahoma Summer Arts Institute at Quartz Mountain State Park. Henson is the poet-in-residence for the State Arts Council of Oklahoma.

Captain Michael L. McCollam (B.A. '74) ... assigned to Randolph Air Force Base in San Antonio, Texas as an instructor pilot.

Susan L. Silver (B.A. '74) ... named news director of KTEW, the

MDC Announces Programs

Ten management short courses designed for persons in the business world will be offered beginning in September by The University of Tulsa Division of Continuing Education.

Academic prerequisites are not necessary for the courses, which meet one evening weekly on campus for eight weeks.

Courses offered are:

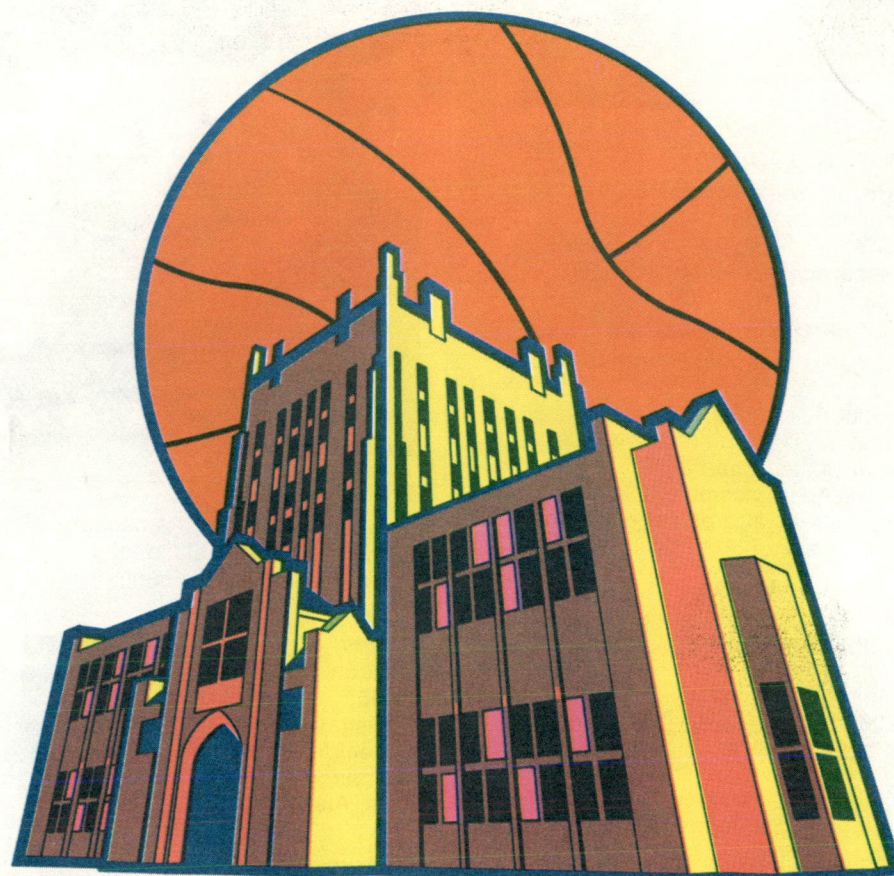
- ☐ **Accounting for Managers (Non-Accountants)** — Directed to persons unfamiliar with accounting but with the need to understand the budgeting and financial process.
- ☐ **Basic Project Management: Planning, Scheduling and Control** — Applies modern management principles with "how to" procedures.
- ☐ **Business Law for Management Decision Making** — A study of practical legal principles to prevent — rather than cure — possible legal problems.
- ☐ **Effective Sales Management** — Principles and practices relating to the management of a field sales organization are emphasized.
- ☐ **Human Resources Development** — Particular emphasis is on manpower planning vs. human resource planning, anticipating

changes, acquiring human resources and administering a human resource plan.

- ☐ **Interpersonal Communications** — A study of the key element to managerial effectiveness.
- ☐ **Planning and Control for Managers** — Designed to show how to decide in advance what kind of future you want and how to get there.
- ☐ **Principles of Management** — An operational analysis of the manager's role in all types of organizations. Deals with the issues of power, authority, influence, decision making, planning, communication and considerations of future trends in organizations.
- ☐ **Small Business Management** — Focuses on unique problems and opportunities faced by managers in smaller firms. Features guest speakers from selected small businesses.
- ☐ **Written Communications for Management Success** — How to put your ideas across effectively in letters, memos, proposals and nontechnical reports.

For further information or registration, call 592-6000, extension 215.

Coach Recruits Juco Stars

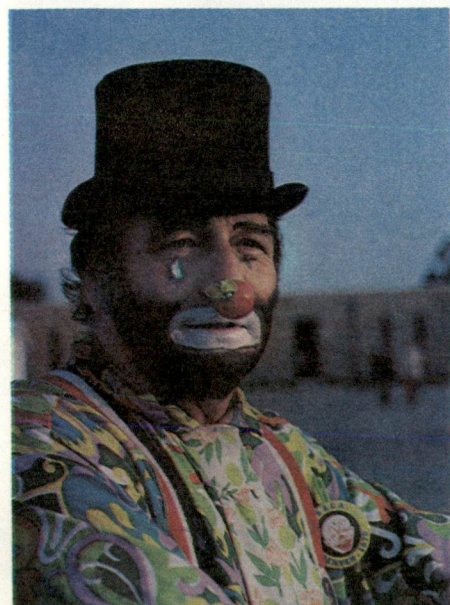


Four players from Western Texas Junior College's national championship basketball team are among the seven recruits signed by new Head Basketball Coach Nolan Richardson.

An early commitment to the Golden Hurricane was made by Paul Pressey, a 6-5 first team juco All-American

Richardson also enjoyed recruiting success outside his own Western squad with help from new Assistant Coach Andy Stoglin, his teammate during their college days at UTEP. The pair combined efforts to sign 6-10 freshman Bruce Vanley, an all-stater from Phoenix, Arizona, and 6-4 freshman guard Brad Laraba from

Stars Come Out For Golf Classic



Big Night Under the Big Top

The University of Tulsa was truly a circus May 28, but it was all for a good cause. The evening was a "thank you" to donors, volunteer leadership, workers and friends who helped the University's Dimensions for a New Decade fund drive exceed its \$43 million goal. The night began with Dr. and Mrs. J. Paschal Twyman, upper left photo, welcoming guests at a reception in the Thelma Ruth Shaw Alumni Center. Photos clockwise: Susie Bitner, director of the University's annual fund, clowns around with Akdar Shrine Temple performers while she prepares the Big Top for guests. Immediate right, guests Jill Hott, Mike and Rita Enright and others were then escorted by Akdar Shriners to the Big Top, where a buffet dinner was served and circus performers entertained. Below, Tulsa juggler Robert York entertains. Bottom right, Dr. Donald Brawner and Homer Wilcox enjoy the evening's festivities. Bottom left, hundreds of balloons ascend at the moment Twyman announces the fund drive's success. Lower left, Mrs. Herman Kaiser visits with friends at table. Immediate left, Akdar Shriner clown looks over the festivities. Center, President Twyman presents campaign general chairman John H. Williams a wood sculpture piece by Artist Brad Place in appreciation of his efforts in the campaign.



Newsman Takes Top A/S Award

ABC news correspondent Bob Brown, a 1968 graduate of The University of Tulsa, has been named recipient of the 1980 Henry Kendall College of Arts and Sciences Distinguished Service Award. The award, established in 1969, is presented annually to a community member or alumnus who has made outstanding contributions to the arts or sciences. Brown is the 10th recipient of the award. Former recipients include Mrs. Gerald H. (Katie) Westby, Jim Hartz, Mary Kay Place, Dr. Harriet Barclay and State Rep. David Riggs.

Dr. Edwin Strong, dean of the college, presented the award to Brown at a dinner at Gilcrease Museum May 10.

"Bob Brown is a dedicated professional who has moved directly and steadily ahead in his career through careful and analytical reporting. We are pleased to honor a former graduate whose successful career had its beginning in Tulsa," Strong said.

Currently a correspondent for the ABC news magazine program "20/20," Brown holds a journalism degree from the University. He has taught newswriting here and was a reporter-anchorman at KOTV-Channel Six. Prior to joining the ABC network in 1977, Brown worked as an anchorman at KHOU-TV in Houston and the ABC Dallas affiliate WFAA-TV. He now resides in Manhattan.

As a network newsman Brown has covered a variety of events, including Elvis Presley's death, Skylab's

degree in 1974, now travels northeastern Oklahoma testing children for possible learning disabilities.

Both Gary and Mark graduated in 1979. Mark received a degree in finance and now works for Feld Trucking Company in sales and marketing. Gary, a criminal justice studies major, is an officer with the Tulsa Police Department.

Last but not least is Karen, who graduated in May with a degree in nursing and soon will join the staff at St. John Medical Center.

The two remaining Otterstrom children attended Tulsa Junior College. Bill is manager of the plant nursery at Binding Stevens. Janice Otterstrom Moeller, who now manages two children, says she also plans to attend the University when her children are in school.

Harold Otterstrom attended MacAlester College in St. Paul, Minnesota, which he calls a "sister" school to The University of Tulsa, because of its Presbyterian heritage. He is retired from the marketing department of Hormel Meat Company, and Mrs. Otterstrom works in the local Weight Watchers office.

For now, Mr. and Mrs. Otterstrom have retired from helping with college homework, sending their children off to college dances and attending University graduation exercises. They enjoy their nine grandchildren and await three more who are on the way. But there's a good chance The University of Tulsa has not heard the last from the Otterstrom family.

— Stephanie Darling

Reading Stressed

Fellow when he wrote a two-volume biography on Faulkner.

Blotner told graduates to "keep the faith" in their commitment to education, particularly by reading classic and contemporary great books. He stressed reading as a method of keeping in touch with events outside one's own area of expertise.

Books provide readers with an awareness of others' efforts to "extend the frontiers of human knowledge," he said. In truly great books, you will find the wisdom of a race."

Blotner also told the audience that the University was "particularly significant" to his own literary profession. He praised the University's Modern Authors Collection, which features rare first editions of all Faulkner's works.

Blotner sprinkled his speech with quotes from Faulkner, whom he considers America's greatest novelist. Faulkner's writing contains wisdom as well as art, Blotner explained.

"Never be afraid to be an individual . . . because man will not only endure, he will prevail," Blotner said, quoting from Faulkner's Nobel Prize acceptance speech in Stockholm, Sweden.

Alumni Host Grad Party

Steamy Oklahoma spring weather couldn't keep a crowd of nearly 1,000 from attending the annual reception for graduates and their families May 11 in Westby Center's Great Hall.

Attendance ran neck-in-neck with last year's record crowd of more than 1,000. Bob Osborne, executive

Winds Favorable For TU Musicians



downfall, the 1980 Winter Olympics and the U.S. visit of Pope John Paul II.

He has conducted two special reports, "Birth Control: The Risk Benefit Factor" and "The Elderly: Out of the Shadows" for ABC's "World News Tonight." He has also anchored "ABC News Briefs" and weekend newscasts.

The author of two high school textbooks, Brown has been named to the new *Who's Who In America*. He is also a member of the American Film Institute.

Seven Degrees For Seven Kids

University Alumni Association Director Bob Osborne could form a complete new alumni club with just one Tulsa family . . . the Otterstroms.

From 1964 to 1980, Mr. and Mrs. Harold Otterstrom saw seven of their nine children graduate from The University of Tulsa. The Otterstrom children have followed a variety of careers, from nursing to police work. Each one helped put her or himself through school.

Pacesetter for the group was Judy Otterstrom Randle, who graduated in 1964 with a journalism degree. She is now editor for the Modern Living section of the Tulsa World and is married to state Sen. Rodger Randle.

James soon followed, graduating in 1967 with a degree in marketing. He is now director of marketing for the Clopay Company in Cincinnati, Ohio.

Russell received a degree in finance in 1972 and now works for the Tulsa Credit Bureau. David, who received a master of education

Reading Exercises By Grad Speaker

University of Tulsa President J. Paschal Twyman conferred degrees on 1,135 candidates during the 83rd annual commencement exercises May 11 at the Tulsa Civic Assembly Center.

During the evening ceremony, Twyman awarded 716 undergraduate degrees, 230 graduate degrees and 189 law degrees. He also presented the University's first Outstanding Teacher award to three faculty members chosen for the honor by their colleagues and students. Recipients of the award were: John W. Hager, professor of law, Chi U. Ikoku, associate professor of petroleum engineering, and Bill D. Jarnagin, associate professor of accounting.

Dr. Twyman also recognized a special member of the audience, Mrs. Henry (Mabel Hall) Waters. Mrs. Waters received an English degree here in 1921, the year Henry Kendall College became The University of Tulsa. She and Miss Eunice McArthur, now a retired school teacher, became the first resident students to graduate from The University of Tulsa. Henry Waters is a 1916 graduate of Kendall College.

Featured speaker for commencement was Dr. Joseph Blotner, English professor at the University of Michigan and one of the nation's foremost authorities on American author William Faulkner.

Blotner, who was a personal friend of Faulkner's, has written several books on the Nobel Prize-winning Southern author. He is a former Fulbright Lecturer on American literature and was a Guggenheim

director of The University of Tulsa Alumni Association, reported. Each year, the Alumni Association sponsors the afternoon reception prior to evening commencement exercises.

Members of the Alumni Association served as hosts and hostesses for the reception. Administration and faculty members were also on hand to honor those receiving degrees.

"Many thanks to all the alumni and others who helped make the reception such a success," Osborne said.

All University graduates received free memberships in the Alumni Association through December 31, 1980.

1980 University of Tulsa Football Schedule



Sept. 13	Cincinnati	7:30 p.m.
Sept. 20	at Wichita State*	7:30 p.m.
Sept. 27	at Arkansas	2:00 p.m.
Oct. 4	Kansas State	7:30 p.m.
Oct. 11	North Texas State	7:30 p.m.
Oct. 18	at Texas Christian	2:00 p.m.
Oct. 25	West Texas State*	1:30 p.m.
Nov. 1	at Florida State	7:00 p.m.
Nov. 8	Indiana State*	1:30 p.m.
Nov. 15	at Southern Illinois*	1:30 p.m.
Nov. 22	at New Mexico State*	1:30 p.m.

*Missouri Valley Conference games

For information on season football tickets, call 592-6000, Ext. 381, or write to Football Tickets, The University of Tulsa, 600 South College Avenue, Tulsa, OK 74104.



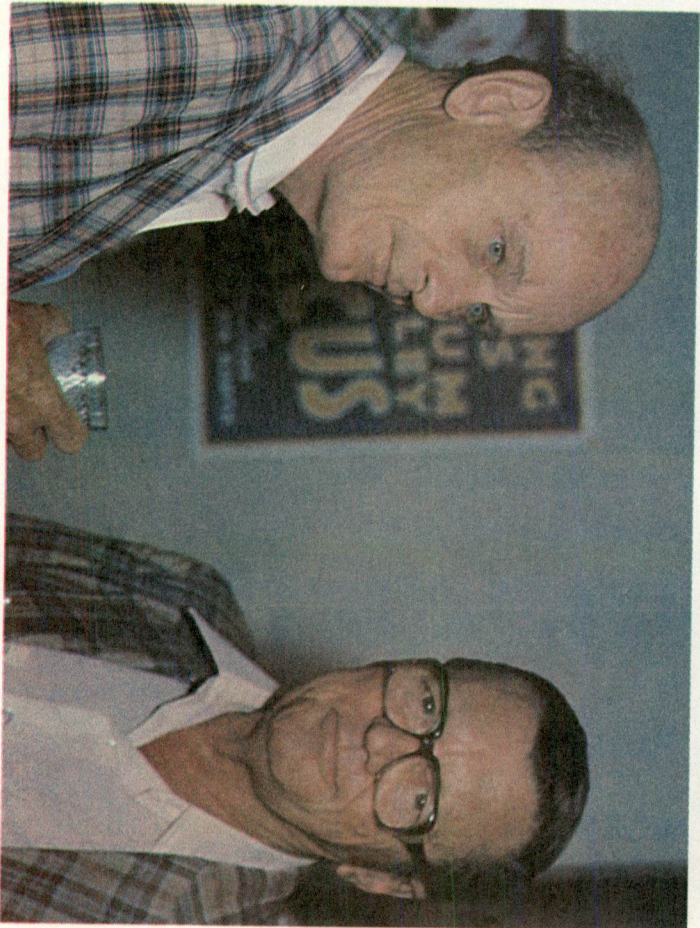
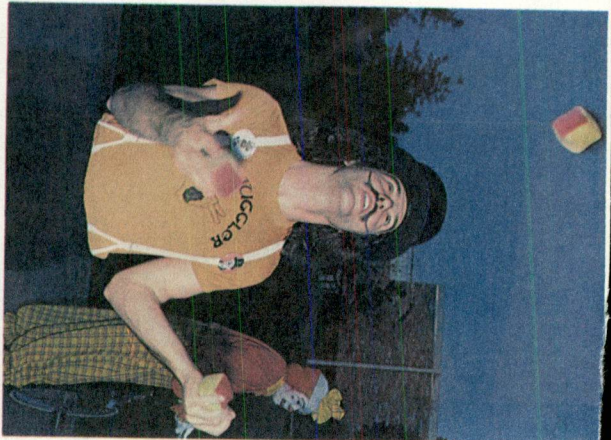
Countless hours of dedication to their art paid off in a trip to Miami Beach for the 45 members of the University's Symphonic Wind Ensemble this spring.

The ensemble was chosen from more than 100 others across the United States to perform at the biennial Music Educators National Conference.

"The opportunity to perform for a national audience is the highest tribute for a university music program," said Ronald Predl, director of the music school. "It is the culmination of 10 years' work."

Joseph Schwantner, who won the 1979 Pulitzer Prize for his orchestral composition titled "Aftertones of Infinity," selected the University ensemble to demonstrate his work "and the mountains rising nowhere . . .," which accompanied the lecture he gave at the convention. In this unique amplified percussion and wind piece, musicians sing, whistle, play glass crystals and use string bows on percussion instruments.

Anna Norbert, assistant professor of music, served as featured pianist during the formal concert performed by the ensemble members. Other selections included: "Centennial Fanfare-March" by Roger Nixon and "English Dances" by Malcolm Arnold, both conducted by Jonathan Good, assistant professor of music and director of bands, and Claude Debussy's "Fetes," conducted by Predl.





In a show of athletic versatility, four University football coaches played a round at the Hurricane Classic golf tournament. Pictured left to right are Coaches Jay Cain, Mike Knoll, Joe Hollis and Head Football Coach John Cooper.

Perfect weather took center stage at the annual Hurricane Classic Golf Tournament in May until several guests stole the show. Gale Sayers, formal all-pro running back for the Chicago Bears, drew a crowd of media representatives, and new Head Basketball Coach Nolan Richardson drew a round of applause as he made his debut on the first tee. The talk of the tournament was the 205-yard hole-in-one shot by 18-year-old Adele Lukken, state high school champion golfer who substituted for her father Bob Lukken. Adele begins her college career at the University this fall.

Winners among the 152 players in the Florida Scramble-style play at Tulsa's Cedar Ridge Country Club were presented at a dinner-dance that evening. First place honors went to the foursome of Ron Furgeson, Max Harbison, Bob Karlovich and Dick Kristinik, who won with an 11-under-par 60. Two teams followed with scores of 10-under-par 61s. University golf coach Mike Alsup (B.S. '78) along with Don Carlock, Art Valence and John Woncik (B.S. '50, M.S. '51) tied for second place with the foursome of Dwayne Gandy (B.A. '58), Dale Haley, Larry Sullivan and Bob West (B.S. '62).

who was named the national tournament MVP at Western. A native of Richmond, Virginia, Pressey averaged 13.9 points, 7.9 rebounds and a total of 170 assists, 126 steals and 53 blocked shots in leading the Westerners to a 37-0 record. He was contacted by nearly every major college team and heavily recruited by Virginia, Virginia Tech, Virginia Commonwealth and other colleges near his hometown.

Also among the newcomers is Greg Stewart, a 6-9 forward/center from Western who averaged 15.9 points and 7.7. rebounds. Twice named to the national all-tournament team, Stewart, of Bronx, New York, was recruited by several major eastern powers and Missouri Valley Conference schools.

The other two Western Texas recruits are Texans David Brown and Phil Spradling. Brown, a 6-7 forward who averaged 12.2 points and 7.1 rebounds, appeared in the national juco all-star game. He was the object of a frantic recruiting battle waged by Hawaii, Texas, Drake, St. Louis and Louisville before finally signing with Tulsa. Spradling, a 6-4 junior, played point guard for Western and averaged 12.6 points and 4.6 assists.

El Paso Burgis High. Vanley, who averaged 15 points with 10 rebounds and four blocks per game, visited Arizona, Arizona State, Northern Arizona and Portland before signing with the University.

Laraba, who averaged 16.5 points and 5 assists per game, was named region MVP. Richardson sees him as a fine prospect with great collegiate potential.

Hoping to fill a void at point guard, Richardson signed 6-0 Mike Anderson, a junior from Birmingham, Alabama, who guided Jefferson State Junior College to a second place finish behind Western Texas in the national championships. Anderson was Jefferson's leading scorer and averaged 18.0 points and six assists. He was named honorable mention All-American, regional MVP, Alabama juco all-star MVP and the outstanding defensive player in the national juco all-star game.

Joining the new recruits are returnees 6-6 Bob Stevenson, who was second team all-MVC; 6-7 Jeff Kovach; 6-10 Ed Lindblad; 6-3 Jim Lacey and 6-3 Ty Nilsson.

— Gil Swalls
Sports Information Director

Special TU Mag Debuts in 1981

A special edition of The University of Tulsa Magazine is being prepared for release early next winter. The magazine will discuss people and contemporary and campus issues through the eyes of faculty and alumni contributors, as well as University Relations staff members.

Alumni interested in contributing to the magazine are invited to write to

University Relations, The University of Tulsa, 600 South College Avenue, Tulsa, OK 74104.

As a special feature, the magazine will contain a new "Letters to the University" column in which alumni and friends of the University can voice their opinions and pass on information to the University, fellow alumni and other readers. Here's your chance to express your views!

exploration and production executive committee of Texaco, Inc., in Harrison, New York.

Donald C. Lane (B.A. '59) ... appointed special judge in Tulsa County.

James D. Pendergrass (B.S.E. '60, J.D. '71) ... named general manager of the Grand River Dam Authority at Vinita.

Bill Scarth (J.D. '63) ... appointed director of the Rogers County Bank board. He is also currently the president of the Claremore school board.

O.A. Griffey III (B.A. '64) ... designated a certified commercial lender by the American Banker's Association. He is vice president at Commercial National Bank in Shreveport, Louisiana.

Jerry D. Fultz (B.A. '65, M.B.A. '68) ... named vice president

Dr. Steven D. Miller (M.A. '67) ... received the Fellowship Award by the Academy of General Dentistry. Dr. Miller practices in Vernon Hills, Illinois.

Dale Gibson (Ph.D. '68) ... spoke at the 85th annual meeting of the North Central Association of Colleges and Schools. He is president of South Oklahoma City Junior College.

E. Ray Harris (J.D. '68) ... named director of tax management for Phillips Coal Co., a Dallas subsidiary of Phillips Petroleum Co.

Carol King, (B.A. '68) ... the only blind teacher in the Oklahoma City school system, was hired last semester to teach a class of legally blind and partially sighted students at Classen High School.

Kitty Roberts (B.A. '68) ... selected one of three Oklahoma women to receive the 1980 Newsmaker Award from Women in

(B.A. '70) ... named senior vice president for Ackerman and McQueen, Inc. advertising agency in Oklahoma City.

Stephen J. Whittington (M.B.A. '71) ... graduated from Officer Candidate School at Newport, Rhode Island, and was commissioned as ensign in the U.S. Navy.

Lex Frieden (B.A. '72) ... has been awarded a fellowship from World Rehabilitation Fund, Inc. of New York. Frieden was selected a 1979 Distinguished Alumni for major community service contributions on behalf of disabled persons.



first woman news director in Tulsa television.

Jere D. Iwata (J.D. '77) ... named a vice president and trust officer at The First National Bank and Trust Co. of Tulsa.

Carl Chaves (J.D. '78) ... opened a private law partnership in Catoosa, Oklahoma. He had been assistant district attorney for Rogers County since 1978.

Martha Spielman (B.A. '78) ... judged this year's Eastern Trails Art Show in Vinita, Oklahoma.

Dugie Standeford (J.D. '78) ... appointed associate bar examiner for the Oklahoma Supreme Court.

Stephen J. Adams (J.D. '79) ... has become city judge in Catoosa, Oklahoma.

The University's baseball program was lowered from a varsity to a club-level sport this spring following a two-year review by the University Athletic Committee, administration and trustees. Baseball Head Coach Gene Shell, in his 15th year with the University, resigned upon learning of plans to deemphasize the sport.

Shell had guided the baseball program to two College World Series appearances and seven Missouri Valley Conference championships.

Dr. Emery Turner, interim athletic director and vice president for administration, said the action had been taken because the program was losing an estimated \$80,000 annually at a time when new demands were being placed on University athletics.

Baseball Team Strikes Out; Veteran Coach Resigns Post

The need to increase support for women's athletics and to add new, lower-cost men's programs to meet the National Collegiate Athletic Association requirements were cited by Turner as the primary causes for deemphasizing the sport.

"Only three sports, football, basketball and baseball, have large enough budgets to make an impact on the rest of the program by being cut," explained Turner. "We needed to save money because we are having

to increase the total number of varsity sports we offer in order to maintain our NCAA Division I status and comply with Federal Title IX regulations concerning equal opportunities for women in athletics."

The University now has eight varsity sports for men and eight for women. Reducing baseball to the club level took away one sport, but cross country is being offered to both men and women as the eighth sport.

The Athletic Committee, a group of students, faculty and other representatives which reviewed the programs noted that baseball, the school's third most expensive sport, has little potential for generating revenue as do football and basketball, and thus is the school's most highly subsidized sport.

Reducing baseball to club level will mean that beginning next spring there will be no new scholarships, no full-time coach and limited travel. The University will help players who wish to transfer to other programs do so without losing eligibility.

Turner said all scholarship athletes who wish to remain at the University will be retained at the same scholarship level for the rest of their four-year program.

Design for Accessibility:

A Traveling Show Sponsored by The National Easter Seal Society

2023 West Ogden Avenue • Chicago, Illinois 60612 • Rita McGaughey, Project Director • Telephone 312-243-8400

NEWS RELEASE

Food Service Operators across the country will learn some new hospitality tips at the 1981 National Restaurant, Hotel and Motel Show scheduled for May 16-20 in Chicago. Featured for the first time in this year's show will be a special program focusing on the growing number of persons who are elderly or have disabilities and who constitute an expanding source of patrons for this country's more than 500,000 restaurants.

Some hospitality tips for serving these patrons have been compiled in a new publication produced by the National Easter Seal Society especially for this year's NRA Show. Tips include suggested techniques for communicating with persons who have a hearing or visual impairment. The importance of directing comments to the person with the disability and not his or her companion is stressed. Also included are tips for making restaurant facilities accessible for those patrons who use wheelchairs or other mobility devices. Some of these tips suggest specifications for parking areas, ramps, toilet rooms, aisle spaces and such wall-hung accessories as telephones and drinking fountains.

The new publication, Tips for Hospitality, will be introduced on Tuesday, May 19, at a specially designed program session that commemorates the United Nations-sponsored International Year of Disabled Persons.

The Easter Seal Society's participation in the NRA Show is part of its "Design for Accessibility" project that is reaching national meetings of professional and trade associations. The project promotes opportunities for strengthening the involvement of the private sector as alternatives to further government regulations for making

(MORE)

buildings accessible to persons with disabilities.

Tips for Hospitality reflects the belief that persons who are elderly or who have disabilities constitute potential markets for American business. Its easy-to-read format is designed to help NRA members extend a welcoming environment to the growing number of these patrons who enjoy the independence of dining out.

Copies of Tips for Hospitality (Pubn. #A-245) may be obtained by sending a self-addressed, stamped, business-sized envelope to Human Resources Department, National Restaurant Association, 311 First St., N.W., Washington, D.C. 20001, or to the National Easter Seal Society, 2023 W. Ogden Ave., Chicago, IL 60612.

* * *

WHAT TIRR IS . . .

The Texas Institute for Rehabilitation and Research was created in 1959 as a voluntary, non-profit, regional health facility to have the greatest flexibility to do what must be done to assist the disabled. It provides care for people of all ages who have been so affected by diseases or injuries that they have a threat to survival and have lost the ability to take care of themselves. The facility was organized for those persons in the State who could benefit from the early comprehensive care and rehabilitation which they require to restore them to healthier physical and psychological condition with the ability to be productive and to take care of themselves as independently as possible. A combined care, research and teaching program was undertaken with Baylor College of Medicine to enhance the quality of service provided.

One of the largest research and training centers in the nation for rehabilitation medicine is conducted at the Institute for the College of Medicine under sponsorship of the Social and Rehabilitation Service. Extensive research on the prevention and control of disability and on ways to restore bodily function and life adjustment is carried out. More than 1200 professional persons were trained last year. Extensive financial help primarily from Houston philanthropy helped to establish and operate the program. The facility was located in the Texas Medical Center to complement the family of essential institutions it contains. There has been no restrictions of eligibility due to income level, place of residence, age, race, or source of sponsorship. The only limitations have been the extent of donations and the capacity of the resource.

We believe that each of us has a right to live and to achieve a useful and productive life in spite of physical handicap.

ON TOUR



Members of the Texas Legislature toured T.I.R.R. on February 1, 1969. In his welcoming remarks to the legislators, their families and their Houston hosts, the Jaycees, Dr. Spencer said, "... this is the smallest hospital that you will see in the Medical Center but we like to think it is the jewel in the crown."

HOW MANY PEOPLE WE SERVE . . .

- In 1968, 1,371 persons from 232 counties of Texas and 121 from other states were helped (see map).
- Since 1959, 7,000 persons of all ages have been helped by the Institute and they required 13,025 admissions to either inpatient or outpatient programs.
- Last year, 1,038 of our patients were under 25 years of age; another 370 were adults 25 to 60 years of age, and 84 were over 60 years of age.

Most people do not know that severe disability is a catastrophic problem of all ages and affects many people during adolescence and young adult educational age periods and older adults of working age. Surprisingly, the average stay in this hospital is only 31 days and for the most severe problems, rarely exceeds 120 days. To help these people, donated funds often had to be found because publicly supported programs are so limited or we had to help those ineligible for such services. \$3,700,000 have been required in the ten years since TIRR was founded.

WHAT KIND OF PROBLEMS OR IMPAIRMENTS TIRR PATIENTS HAVE . . .

Disorders of movement, sensation, vital

functions and brain function usually due to:—

- Extensive paralysis*—resulting from spinal cord injury (largely due to auto accidents and athletic injuries); or due to brain injury or damage from poor circulation or vascular disease causing a stroke, or due to diseases of nerves and muscles.
- Multiple handicapping conditions*—due to birth defects, diseases of nerves and muscles, skeletal system deformities, amputations, inflammatory conditions such as a severe arthritis, and diseases affecting the general chemistry of the body, etc.
- Breathing impairments*—due to cystic fibrosis, childhood illnesses affecting the lungs and circulatory system or where there is nerve and muscle damage causing weakness or paralysis of the muscles.

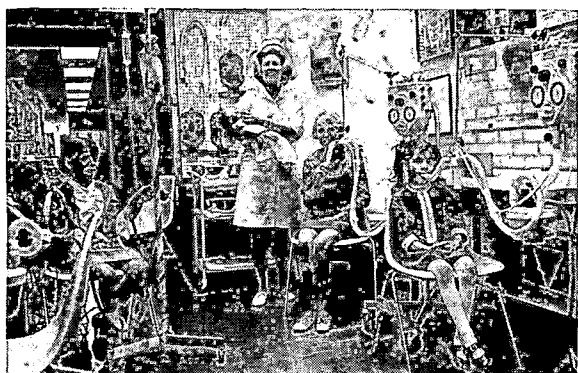
Orthotics

A great many of our patients have spinal cord injury, most often caused by sports or automobile accidents, and resulting in paralysis of the legs and if the injury is high, paralysis of the hands as well." Here in the Orthotics Department, Representative Allred takes a close look at the way in which movement of the hand is restored to Mr. Hank Emerick, a TIRR "graduate", with a hand splint type of assistive device. This device is externally powered with a specially designed control valve to activate the release of carbon dioxide into a tubular muscle substitute. When the muscle substitute is inflated with gas, it shortens—thus moving the thumb and fingers together to grasp a pencil, a telephone, a fork, the objects of everyday activities.

"This equipment was developed on a research grant from the Social and Rehabilitation Service of the Department of Health, Education and Welfare, and we have applied it to over 85 people with paralysis."

Cystic Fibrosis Clinic

In the Cystic Fibrosis Clinic, first stop on the tour, visitors met "children who have an 'invisible' handicap. C.F. children often look very healthy but they require daily inhalation therapy treatment to combat the excess of mucus in their lungs, caused by this hereditary disease. The Institute has an education program for parents so that they can learn to carry out treatment at home. Over 300 C.F. children are currently receiving help from the Institute."





HOW COMMON THESE IMPAIRMENTS ARE IN OUR POPULATION . . .

Most of the people helped at TIRR are handicapped by injuries or conditions over which they have no control and which drastically affects most of their activities of living. Nearly every person facing a catastrophic illness or injury is pauperized by the costs, save for job-connected injuries. There are no truly accurate figures on the incidence of severe handicapping conditions but estimates from health surveys suggest 10% of the population have chronic, non-curable medical conditions causing disability which severely limits the function of the person. We have helped over 800 totally paralyzed persons from accident-caused spinal cord injuries alone!

Research

Mr. George Miller, an amputee involved in a research project, demonstrated the way in which information is collected about the fit of an artificial leg. "Electronic instruments measure the pressure exerted on the artificial leg, the angle of flexion of the knee, and the time at which the heel, mid-foot, and toe of the foot strikes the floor."

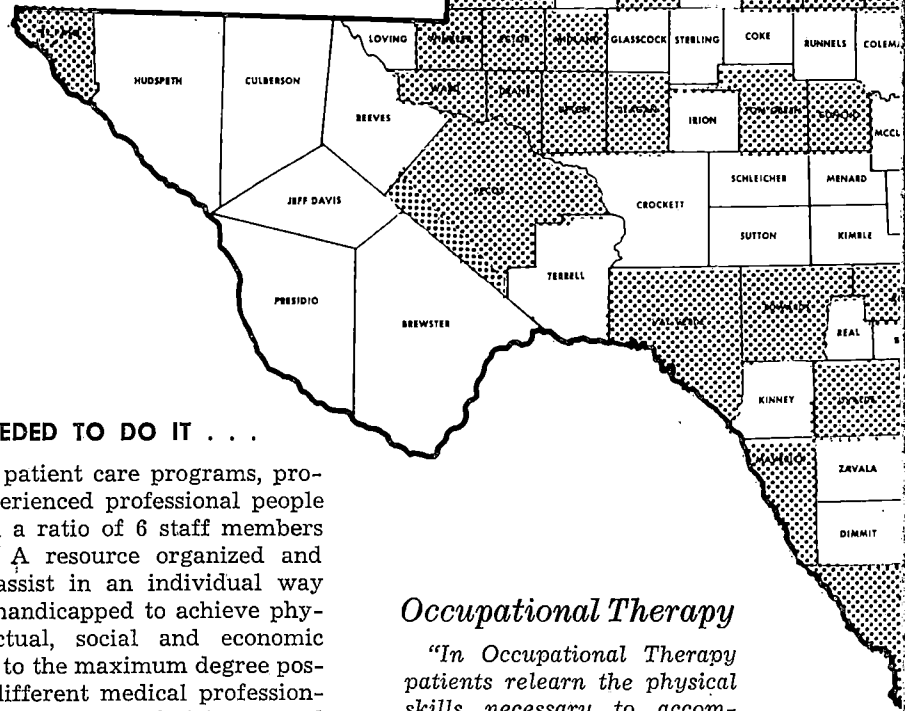


Vocational Unit

"It is in the Vocational Unit that we see the culmination of our objectives . . . last year over 90 people achieved gainful employment through this program."

WHAT CAN BE ACCOMPLISHED . . .

The person with multiple handicaps, or severe impairments, given early and comprehensive care and rehabilitation, if a child, usually returns to family and school life. More than 1/2 of our adult graduates are engaged in homemaking or remunerative work. *Ninety percent* have been able to live independently of institutional residence.



WHAT IS NEEDED TO DO IT . . .

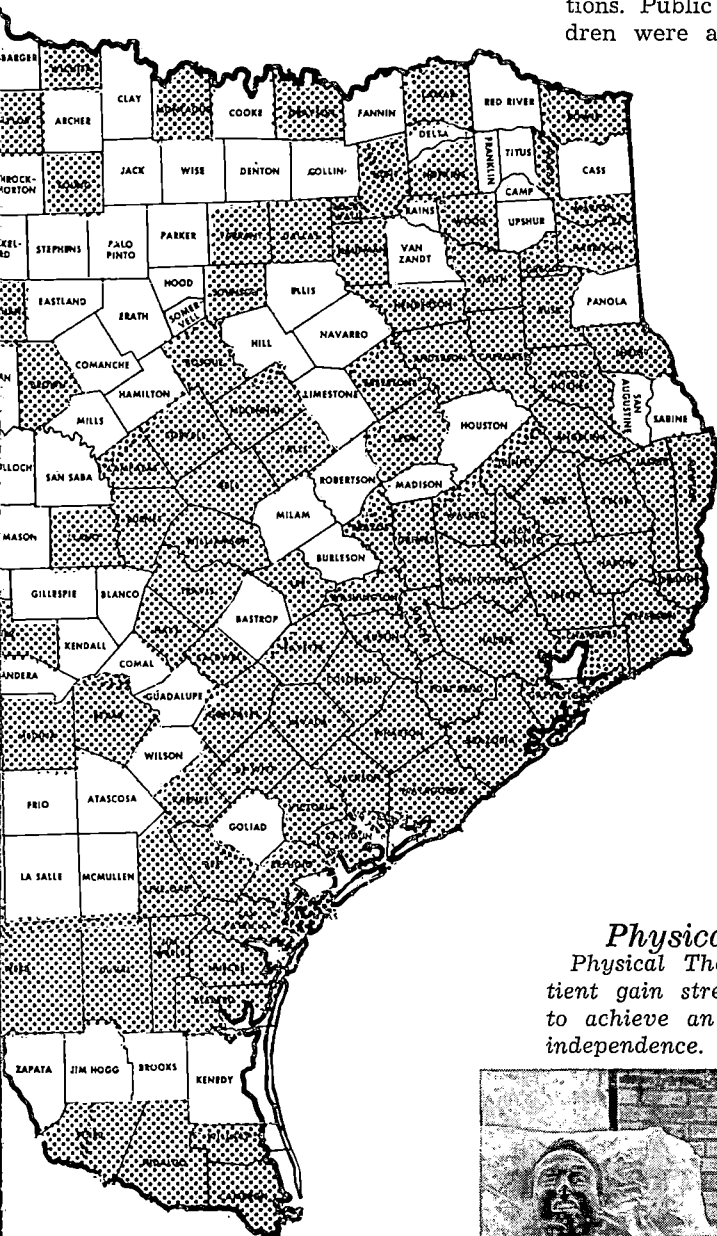
Specialized patient care programs, provided by experienced professional people and aides—in a ratio of 6 staff members to 1 patient. A resource organized and operated to assist in an individual way the severely handicapped to achieve physical, intellectual, social and economic independence to the maximum degree possible. Many different medical professionals, co-professionals, technicians, and aides are required who, by team work and under medical leadership, coordinate their efforts to control serious medical problems, to restore lost personal function and to develop personal potentials. Training of the patient and family in the follow-through program preserves the gains of rehabilitation and exploits every opportunity for independent living, work or education. Clinical research is directed to the problems of care and the improvement of the methods and techniques of rehabilitation. Every advance in science and technology is used which increases the function of the handicapped person and improves the efficiency of serving them at the lowest possible cost with maximum benefit.

Occupational Therapy

"In Occupational Therapy patients relearn the physical skills necessary to accomplish the activities of daily living. We want to help them to be as independent as possible when they return to society."



COUNTIES OF RESIDENCE OF TIRR PATIENTS - 1968



In Physical Therapy, Mr. Kelly Balingier visits with his Representative, Jack Ogg. The standing bed Mr. Balingier is using was devised to prevent calcium loss and increase circulation and, in cases of spinal cord injury, to increase the patient's tolerance to an upright position, a few degrees at a time, without the drop in blood pressure that these patient's experience.



WHAT IT COSTS TO DO IT . . .

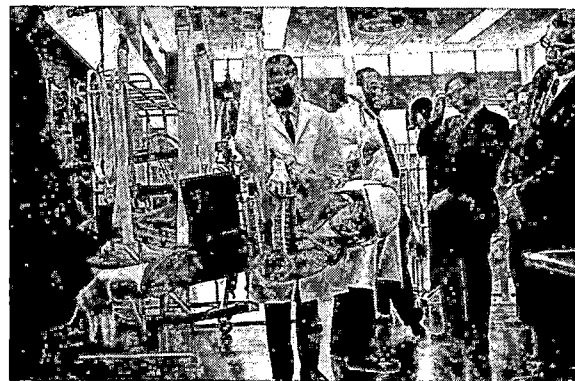
A recent study of 1,000 patients provided comprehensive services at the Institute showed that the average cost for the initial complete program was \$4,376 (excluding physicians' services which were donated). It was necessary to find on the average 2.3 sponsors; no one had resources to pay all costs; 18% of the cost had to be provided by private donations. Public (state) programs for children were available to only 1/2 of the

children and this provided only 19% of the total cost. Vocational rehabilitation sponsorship for young adults was available to only 1/2 of them and only 18% of the cost of care was provided. Cost is related to the care problems to be solved, their severity and to what extent they can be resolved by an individualized plan of care extending from early medical treatment through vocational and educational assistance.



WHAT IT COSTS NOT TO DO IT . . .

Most medical advances prolong life but do not necessarily improve the quality of the life remaining. Formerly, prolonged nursing home or other custodial maintenance of life was the severely disabled person's fate. Custodial care of the spinal cord injured with a life expectancy of at least 25 to 30 years means an expenditure exceeding \$100,000. Modern comprehensive care and rehabilitation excluding medical costs for the quadriplegics averages \$9,400 with \$1,000 per year of maintenance costs and equipment—a bargain! More than 1/3 become taxpayers or free another person to work.



"We have a new development to help patients—a Reduced Gravity Simulator—the design for it came to us from the people in space research. They developed it to teach their astronauts to walk in space. We are developing it to help patients exercise and carry out gait training by placing them in an atmosphere of reduced gravity."

WHY SUCH PROGRAMS ARE IMPORTANT TO THE STATE . . .

If we are to harvest every human potential, decrease the cost of dependency and learn to overcome the adversity of illness and injury or defect, there are few alternatives appropriate to a responsible and humanitarian society.



WHAT THE PROBLEMS ARE IN EXPANDING SUCH SERVICES...

- availability of rational, non-fragmented, inclusive or coordinated financial sponsorship of care and rehabilitation services (private donations are becoming less and less available unless matched by public tax money).
- lack of resources of trained people, facilities and an informed public.
- lack of appropriate partnership both public and private to help those needing help—who will benefit by it and who are most likely to return to a useful, meaningful life if afforded a proper opportunity.
- legal, administrative, public facility, and social barriers of the handicapped to get help and to return to the normal mainstream of life including the opportunity for work and recreation.

"On Nursing Station 111, our center for patients with spinal cord injuries, we have daily treatment schedules, generated by a computer, for each patient in the center. The schedule shows what is to be done for each patient, when and where it is to be done, who is to do it, and each day's changes in treatment plans. The computer also provides, to individual departments, listings of the patients that they are to treat, including what the department is expected to do and so forth. The computer helps us to serve the patient most efficiently and at the same time, reduce hospital costs."



Representative Murray signs the register. Mrs. Jane Taylor, volunteer, stands at right.



L to R.—Representative Nichols, Representative Kothmann, unidentified couple, Dr. Spencer, Dr. Eastwood and Representative Harding.

WHAT THE SOLUTIONS ARE...

- adequate, rational public financing based on public need and availability of services complementary to available insurance and personal resources.
- expanded regional service resources—utilized by hospital tax authorities whether public or private to avoid duplication of scarce resources.
- earlier care which limits or minimizes needless disability at lower cost with lessened public dependency.
- an informed public and public servants cooperating with professionals for the best usage of what is available to those who need it and who can be helped.

HOW THE LEGISLATURE CAN HELP SPECIFICALLY

- give attention to the needs of the disabled and the barriers they face, social as well as physical, through expanded fiscal and administrative support including a non-restrictive separate *Rehabilitation Agency*.
- give priority to severely disabled simply because without help they are left to custodial care without a second chance to live a worthwhile and dignified life.
- provide full State matching of Federal funds available for programs that are *exclusively* state-controlled for expanded services and resources (both public and private, non-profit).
- implement contractual arrangements with private as well as public institutions for needed services paid for in either case on an *actual cost basis*.
- correlation of public and private benefits to protect the patient's chance for help at the right time and to the degree needed.
- encourage a means test based on *existing* need instead of previous income level.
- provide fiscal incentives to organized facilities providing better care at lower per patient program costs.
- foster expanded research and education.

On the Verge: The Transformation of Long-Term Services and Supports

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Many states are undergoing or are about to undergo a dizzying array of long-term services and supports (LTSS) transformations. The lagging economy and increased demand for publicly funded LTSS are placing pressure on state policymakers to find solutions. As a result, many states either have or plan to implement Medicaid Managed LTSS, with 12 states having existing programs and another 11 with plans for implementation. At least 28 states are focusing on improved integration of care for people who are eligible for both Medicare and Medicaid. Many states used the economic downturn as an opportunity to balance services from institutional to noninstitutional settings, with 27 states reporting that home and community-based services census increased from fiscal year (FY) 2010 to FY 2011 and 31 states reporting expected increases from FY 2011 to FY 2012.

This In Brief summarizes a research report, *On the Verge: The Transformation of Long-Term Services and Supports*. The report presents the findings from a state survey conducted in fall 2011. State aging and disability agencies and Medicaid agencies from 48 states and the District of Columbia responded with long-term services and supports (LTSS) information on programs for older people and adults with physical disabilities.

State LTSS Transformations

Many states are on the verge of transforming the financing and delivery of LTSS. On the heels of the Great Recession, state policymakers are looking at solutions that include moving toward capitated, risk-based managed care for Medicaid enrollees with LTSS needs and focusing on better care and

cost containment for people who are dually eligible for both Medicare and Medicaid coverage (dual eligibles).

Many states either have implemented or plan to implement Medicaid Managed LTSS for individuals with LTSS needs, with 12 states having existing programs and another 11 with plans for implementation in 2012 or 2013. About half of the 11 states that are implementing Medicaid Managed LTSS have definite plans to implement statewide. At least 28 states are focusing on improved integration of Medicare and Medicaid services for dual eligibles.

Budget Cuts and Increased Demand

The lagging economy remains a growing concern for state agencies. States have used many administrative tools to curtail

expenditures. At the same time, demand for publicly funded services has grown, and resources, including staff, are stretched thin.

Although fewer states made cuts to LTSS in fiscal year (FY) 2011 than in FY 2010, 14 states made cuts to aging and disability services programs (non-Medicaid) in FY 2011. Eleven states were expecting to cut these programs in FY 2012. It is important to remember that even in the states that did not make reductions in this fiscal year, many states have sustained three years of consecutive budget cuts. Fewer states made cuts to Medicaid programs; most Medicaid cuts targeted provider rates. A handful of states, however, imposed restrictions to some Medicaid services, most notably personal care services.

Requests for services increase during an economic downturn because people have less income and assets and therefore qualify for government programs. While enrollment typically increases with more families and children qualifying, more than half of the states reported increased demands for Aging and Disability Resource Center services, information and referrals, and respite care in FY 2011.

Balancing Prioritized

Many states are using the economic downturn as an opportunity to balance services from institutional to noninstitutional settings. States continued to serve a greater number of Medicaid recipients with LTSS needs in their homes or communities. Of 37 responding states, 27 reported that home and community-based services census increased from FY 2010 to FY 2011, and 31 reported expected increases from FY 2011 to FY 2012. Twenty states reported that they expected the number of Medicaid nursing facility residents to decline, and nine expected the number to remain unchanged from FY 2010 to FY 2011. Only seven

expected the nursing facility census to increase. Surprisingly, many states were able to preserve their small but important non-Medicaid, state-only funded programs, which often serve people who do not qualify for Medicaid.

Staffing Changes and Reductions

There was a record number of new state officials in 2011, with 26 new governors, 40 new state aging and disability directors (78 percent turnover) and 11 new Medicaid directors (20 percent turnover). Reducing overall state aging and disability staff rather than cutting services continues to top the list of current and planned savings strategies.

Uncertainty of the Affordable Care Act

The recent health care reform law provides states with options to expand home and community-based services, yet many states are reluctant to commit to some of these programs because of litigation pending before the U.S. Supreme Court. States also are waiting for final federal implementation guidance.

In Brief #INB 196, February 2012

This In Brief is a synopsis of the AARP Public Policy Institute Research Report #2012-02 by Mike Cheek, Martha Roherty, Leslie Finnan, and Eunhee (Grace) Cho, National Association of States United for Aging and Disabilities; Jenna Walls and Kathleen Gifford, Health Management Associates; Wendy Fox-Grage and Kathleen Ujvari, AARP Public Policy Institute. AARP Public Policy Institute
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