



## Access to Health Care for People with Disabilities

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### In This Issue...

**Kristi Kirschner, MD**

Director

Donnelley Family Disability Ethics Program

I launched my career as a new attending physician on the RIC spinal cord unit in 1990 -- the same year that the Americans with Disabilities Act (ADA) passed. As a resident physician, most of my experiences with patients had been fragmented--largely due to the rotational nature of the training programs. Once I had my "own" patients in my attending role, I developed a deeper understanding of their fears, concerns and experiences with the health care system. A troubling theme began to emerge: Many of my patients perceived doctors and hospitals as frequently unwelcoming and sometimes frankly discriminatory.

I felt stymied. I had been trained to make medical recommendations, not to figure out the logistics of basic access. With a lot of support from RIC administration, my colleague Dr. Suzan Rayner and I started a reproductive health care clinic for our female patients in 1991. This was really a stop-gap measure. If our women weren't able to access gynecological care in the community, we would bring the services to RIC. Yet such a move was really antithetical to the spirit of the ADA. Our mantra became that true success would be measured when the gynecological clinic could CLOSE because there were many accessible community alternatives and it was no longer needed. We are still far from that day.

With the passage of the ADA in 1990, we expected big changes in short measure. In some areas the changes have been fairly dramatic--such as in public buildings, communication and transportation services.



Summit on Healthcare Access for People with Disabilities

But in other areas such as health care, little seems to have changed. On a weekly if not daily basis, I hear stories of patients who encounter barriers in the health care setting-- from inaccessible examination tables, mammogram machines, radiology equipment, and bathrooms to prejudice and lack of basic disability knowledge by health care staff and physicians. Fortunately, there is growing interest and momentum from a number of sectors to solve these problems. In this issues of *Ethics Matters*, we highlight some of these initiatives.

On the next page, DR. MaryMargaret Sharp-Pucci introduces the summit on health care for people with disabilities which the RIC Donnelley Family Disability Ethics Program and Women's with Disabilities Center hosted in partnership with the Disability Rights and Education Defense Fund (DREDF) in April 2008. The summit was funded by the National Council on Disability (NCD), with the goal of developing policy recommendations to address health care access problems. Rev. Mary Stainton, a woman with Cerebral Palsy, tells her story of difficulty accessing a radiological examination that required her to stand. Ms. Kaylan Dunlap highlights Universal Design--an idea still in its infancy but arguably one

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of the most exciting and commonsense paradigms for addressing health care access problems.

Dr. Kiyoshi Yamaki and Ms. Carol Cox describe the Illinois Disability and Health Program, an initiative funded by the U.S. Centers for Disease Control and Prevention, to address practical strategies to improve health care access for people with disabilities. Dr. Sandra Gaynor follows with a description of the Ticket for the Cure grant awarded to the RIC Women with Disabilities Center to develop training materials for mammography technicians to better accommodate the needs of women with disabilities. We close with a book review by Ms. Judy Panko Reis for More Than Ramps, a rich seminal resource by Dr. Lisa Iezzoni.

We hope you find this issue of our newsletter informative. We welcome your comments and feedback!



Health Care Access Summit participants

## RIC Hosts Ground-Breaking Health Care Summit: Focuses on Readily Achievable Gains

by **MaryMargaret Sharp-Pucci, PhD, MPH**



Dr. Joanne Smith, RIC President and CEO, addresses Summit experts

An influential group of policy-shapers, thought-leaders and decision-makers in disability and health care met on the Rehabilitation Institute of Chicago (RIC) campus in April to convene the "2008 Summit on Health Care for People with Disabilities."

According to summit participants, navigating the health care system continues to stand out as a significant source of

frustration and distress for people with disabilities. Eighteen years after passage of the Americans with Disabilities Act (ADA 1990), health care in the United States is still not accessible to people with disabilities. People with disabilities continue to bear a disproportionate burden of poor health compared to the general population. The poor health outcomes are not necessarily associated with the individual's disability. They are often the result of barriers to access and unequal quality of health care.

The National Council on Disability (NCD), an independent federal agency making recommendations to the President and Congress, provided funding for the initiative as part of a larger research effort to advance the state of health care for people with disabilities. The Summit was spearheaded by Kristi L. Kirschner, Director of The Donnelley Family Disability Ethics Program at RIC and Mary Lou Breslin, Senior Policy Advisor at the Disability Rights Education and Defense Fund (DREDF) in Berkeley, California.

DREDF is currently preparing the Summit's final report for the NCD. Once NCD releases the report, we will provide greater detail about the Summit and its recommendations.



## All I Needed Was A Simple X-Ray

by Rev. Mary Stainton, MDiv

I am a 50-year-old woman who uses a power wheelchair. For almost a decade now, I have been a regular visitor at my neighborhood medical center: One of the first things every doctor asks me is, "Why are you in a wheelchair?" One of the first things I tell them is, "I have Cerebral Palsy." In the Fall of 2006, a doctor diagnosed me with gastro esophageal reflux disease. Treating GERD seemed simple enough: Take a pill and the damage gets repaired; symptoms disappear. I did take a pill. The symptoms didn't disappear.

"I think we need to do an endoscopy," said the GI specialist he sent me to.

I scheduled the procedure, and went in to have it done a few days later. My body sat in its usual "S" shape as I waited for the nurse. Aging had also brought scoliosis. A nurse arrived and asked,

"Can you get onto a stretcher by yourself, or do you need help?"

"I need help. You'll need to get some people to lift me."

"They weren't able to do the endoscopy," said the nurse as I woke up. "They tried to get the tube in you, but you gagged. We'll have to do an x-ray."

She made an appointment for me. As I left, she handed me a copy of the order and gave me instructions not to eat anything during the twelve hours prior to the procedure. I glanced at the diagnoses: GERD and--someone had written in large blue letters--"Cerebral Palsy."

I was an hour early for the x-ray and they were an hour late getting to me. During those two hours, I rolled up and spoke to a person in the reception area twice, once to give someone the piece of paper which said I have Cerebral Palsy. At last, I heard a woman call my name. I followed her into a room. For a minute, she stared at me.

"Can you stand?" she asked.

"No."

She walked away and whispered to her colleague, then returned and stood in front of me.

"The test requires you to stand."

I looked at her as anxiety turned to anger.

Twelve hours with no food for nothing! was my first

thought, followed by, why didn't they tell me this when I went to the receptionist desk two minutes after I got here? Wouldn't anyone who looked at me for even thirty seconds question whether I could stand? Why did anyone make me come in for this test at all?

"I gave the receptionist a piece of paper which states I have Cerebral Palsy," I said, "and it is written all over my medical records that I have CP. Cerebral Palsy is a common disability, and it is common for people with CP not to be able to stand. You are either ignorant about Cerebral Palsy, in which case you needed to look it up, or you are ignorant about ways to adapt this procedure for someone who cannot stand."

"I'm sorry," said the technician.

I left the room.

If you would like more information on Cerebral Palsy, you can go to the United Cerebral Palsy website at [http://www.ucp.org/ucp\\_generaldoc.cfm/1/9/37/37-37/447](http://www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447).



Rev. Mary Stainton, M.Div.

# Universal Design

by Kaylan Dunlap, LPTA

Accessibility Specialist, Evan Terry Associates, P.C.

Imagine a mother with a baby in a stroller and a toddler tagging along, trying to open the front door to the pediatrician's office. Imagine a wheelchair user leaving his urologist's office and trekking across campus at a large medical center to another appointment at the MRI center. Imagine a woman who uses sign language in the emergency room trying to communicate her symptoms and questions to the hospital staff, who are trying to diagnose their patient. Universal Design is a concept that benefits the people in these examples, and all patients, visitors and staff in hospitals and clinics every single day. When applied, Universal Design improves buildings and services so that they are usable by all people, regardless of ability.

In a Universally Designed environment, the mother of two young children would not have to open the door and put her foot against it to keep it open while she maneuvers the stroller through while trying to keep her toddler going in the right direction. If an automatic door were provided, the doors would open when the motion sensor detected her presence, and she and her troop would walk straight into the building without stopping. The wheelchair user would go to the shuttle stop just outside the entrance of the office building and board a shuttle bus using a wheelchair lift that would take him to the entrance of the hospital where the MRI center is located, keeping him out of the extreme heat and helping him to be on time for his next appointment. The woman in the emergency room would be provided with a medical sign language interpreter or an online service that also offers foreign language interpretation to facilitate communication between the patient and the hospital staff so that a comprehensive diagnosis and plan of care could be determined and implemented.

The Americans with Disabilities Act (the ADA) prohibits discrimination against persons with disabilities, facilities, programs and services that are provided by healthcare entities. Universal Design encourages businesses to go beyond the minimum requirements of the ADA, with the ultimate result being that patients are treated as individuals; buildings are more usable and safe; and policies and procedures are developed and maintained so that programs and services benefit everyone. Healthcare facilities and providers should consider Universal Design in a team approach to the care of individuals. An accessibility coordinator on staff can coordinate the purchase, maintenance, and use of accessible medical equipment and auxiliary aids; monitor and respond to complaints;

(cont. on p. 6)

## Principles of Universal Design

### Principle One: Equitable Use

—the design is useful and marketable to a wide range of individual preferences and abilities

### Principle Two: Flexibility in Use

—the design accommodates a wide range of individual preferences and abilities

### Principle Three: Simple and Intuitive

—use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level

### Principle Four: Perceptible Information

—the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities

### Principle Five: Tolerance for Error

—the design minimizes hazards and the adverse consequences of accidental or unintended actions

### Principle Six: Low Physical Effort

—the design can be used efficiently and comfortably and with a minimum of fatigue

### Principle Seven: Size/Space for Approach and Use

—appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility

*From the Center for Universal Design, North Carolina State University, Raleigh, NC*

[www.design.ncsu.edu/cud/](http://www.design.ncsu.edu/cud/)

(Universal Design, cont. from p. 4)

and review and implement improved policies and procedures. Training for all employees could be provided on interacting with people with disabilities and safety techniques to be used when assisting patients with disabilities. Pre-admission paperwork should include questions about a patient's special needs so that accommodations can be made prior to admission. These special needs could be the need for a foreign language or medical sign language interpreter, use of a mobility device, the need for assistance with transferring, or the need for enlarged text or Braille materials. Patients who require assistance with transfers and dressing may need a longer appointment time than others. Having policies in place to provide these patients with longer appointments and trained staff who know how to schedule these appointments prevents other patients from having to wait in the waiting room.

Architectural design is not the only way Universal Design can be applied to healthcare. Choice of furniture can also reflect Universal Design. For example, an exam table that is height adjustable has numerous benefits: it gives the patient using a wheelchair or scooter an opportunity to transfer onto the table, perhaps independently, without having to be lifted by a caregiver or staff to a high table. It allows the physician to perform a complete exam that could not be carried out with the patient in their wheelchair, encouraging a more comprehensive exam. It reduces the risk of back injuries to caregivers and staff that are assisting with lifts from wheelchair to exam table. And it increases patient safety by eliminating the need for children, elderly, or short stature patients to climb up onto the table. Offering chairs of differing heights, widths, and types (with or without armrests, hard or padded seats) in a waiting room provides more options to patients and visitors. Careful placement of furniture in the waiting room can provide spaces for wheelchairs, scooters, and strollers to park out of the path of travel. Another area with a high need for Universal Design is the development of website design and content and of literature that provides information about available services, such as: locations of accessible parking, entrances, and toilet rooms (including family toilet rooms); and information in many different languages, including the availability of medical sign language interpreters.

Healthcare needs are changing as the population ages. There are many opportunities to provide Universal Design in the healthcare setting. The Center for Universal Design at North Carolina State University publishes the brochure "Removing Barriers to Healthcare" that can be ordered or printed from their website: <http://www.fpg.unc.edu/~ncodh/pdfs/rbhealthcare.pdf>. Additional information can be found on the Public Access Section of the U.S. Department of Justice's website at [www.ada.gov](http://www.ada.gov).

## Additional Resources on Accessible Health Care/Universal Design

1. *It Takes More Than Ramps to Solve the Crisis of Healthcare for People with Disabilities.* [http://www.tworldwide.com/events/hhs/041206/PPT/RIC\\_whitepaperfinal82704.pdf](http://www.tworldwide.com/events/hhs/041206/PPT/RIC_whitepaperfinal82704.pdf)
2. *Health: Access to Care.* <http://www.dredf.org/healthcare/index.shtml>
3. *Guidelines: Making Health Settings and Information Accessible.* <http://www.cdc.gov/nccdd/dh/accessibilityguides.htm>
4. *Removing Barriers to Health Care: A Guide for Health Professionals.* <http://www.fpg.unc.edu/~ncodh/pdfs/rbhealthcare.pdf>
5. *Applying Universal Design to Medical Devices.* <http://www.devicelink.com/mddi/archive/03/01/006.html>
6. *5 "G's": Getting Access to Health Care for People with Physical Disabilities.* <http://www.cdihp.org/5%20Gs%20aug08.pdf>
7. *Providing Primary Health Care for People with Physical Disabilities: A Survey of California Physicians.* <http://www.cdihp.org/pdf/ProvPrimeCare.pdf>

# Persons with Disability Can Be Healthy: A New Approach to Disability and Health

by Kiyoshi Yamaki, PhD, University of Illinois at Chicago

and

Carla Cox, MPH, CHES, Illinois Department of Public Health

Having a disability does not mean a person is in poor health. Persons with disability can be as healthy or even healthier than persons without disability. A person can maintain good health by using disease prevention services and health promotion practices such as flu shots, oral hygiene exams, and cancer screenings. A person can become healthier through daily lifestyle changes such as practicing better personal hygiene, engaging in more physical activity, and eating nutritious foods.

Because persons who have disability are more likely to be physically inactive, overweight, and/or have high blood pressure and high cholesterol than those without disability, they are susceptible to developing additional chronic diseases and health problems that are related to, or made worse by, the primary disability ("secondary conditions"). Despite this elevated health risk, disease prevention and health promotion services have not been readily available to persons with disability. Addressing this gap, the Illinois Disability and Health Program is a statewide initiative to promote the health of Illinois citizens with disability by facilitating inclusion of persons with disability in ongoing health services and health promotion programs in the state.

The Illinois Disability and Health Program is a joint effort of the Illinois Department of Public Health and the University of Illinois at Chicago. In July 2007, the Illinois Department of Public Health received a five-year grant from the U.S. Centers for Disease Control and Prevention (CDC) to establish a program to reduce and prevent secondary conditions (including pain, fatigue, depression, obesity, and chronic health problems that are related to or made worse by primary disability) among Illinois citizens with disabilities and to improve their health, well-being and quality of life.

During the first year of the grant, activities included:

- ◆ building capacity by maintaining and expanding the Illinois Disability and Health Partnership, a statewide advisory group for the project that includes disability advocacy organizations, other state departments, local health departments, health advocacy organizations, and university-based programs;
- ◆ collaborating with other chronic disease programs within the Illinois Department of Public Health, as well as external partners, to deliver health education to persons with disabilities and to health care providers;
- ◆ increasing communication among partners;
- ◆ publishing an Illinois Disability and Health State Plan and an Illinois Disability and Health Data Report to increase awareness of health related disability issues; and
- ◆ developing four work groups to plan and carry out health promotion activities for persons with disability. These work groups include:
  1. Health Promotion -- focuses on identifying target groups, resources and materials and developing and using evidence-based awareness and education programs.
  2. Professional Development -- focuses on identifying professional target groups and on exploring ways to increase disability awareness among health care professionals.
  3. Service Accessibility -- focuses on promoting accessible health care and support services to increase independence among persons with disability.
  4. Surveillance and Data -- focuses on maintaining and expanding existing data on the prevalence and impact of secondary chronic conditions among persons with disability and providing data support to state and local data users and Partners.

Anyone who is interested in disability issues is invited to join this endeavor. For more information on the Illinois Disability and Health Program contact Carla Cox, Program Coordinator, at [Carla.Cox@illinois.gov](mailto:Carla.Cox@illinois.gov).

Both the Illinois Disability and Health State Plan and the Illinois Disability and Health Data Report mentioned above can be found at [http://www.idph.state.il.us/HealthWellness/disability/Disability\\_Health\\_Plan\\_2007-2010.pdf](http://www.idph.state.il.us/HealthWellness/disability/Disability_Health_Plan_2007-2010.pdf).



# Ticket For The Cure

by Sandra Gaynor, PhD, RN

Executive Director, Council for Public Interest in Anesthesia

Director AANA Wellness Program

Breast cancer is a public health concern for all women. Despite national objectives to promote the health of women with disabilities, the use and quality of preventive breast cancer screening by women with disabilities remains inadequate. A lack of regular screening leads to delays in breast cancer diagnosis and less favorable prognoses. Women with disabilities are more likely to be diagnosed at a later stage of cancer than their non-disabled peers. Women with disabilities have life expectancy similar to the non-disabled population and as a result many women who fall within the age group at highest risk for breast cancer (50-59) will lack adequate screening. The Centers for Disease Control (CDC) has identified specific barriers to breast cancer screening for women with disabilities. These barriers include: lack of accessible screening facilities and equipment, difficulty with positioning, and provider knowledge and attitudes.

As one of the first recipients of the State of Illinois Ticket for the Cure Program Grants, the Women with Disabilities Center (WWDC) at RIC developed and implemented a continuing education program for radiology technicians and mammographers. The objective of the program was to improve the effectiveness of mammography screening among women with physical, sensory, emotional and cognitive disabilities. A collaborative team was gathered to represent the many audiences involved in this effort. Three mammographers, administrative staff from two screening centers and community representatives from three different disability groups participated.

The curriculum, "Conquering Mammography Positioning Challenges" was developed as a group effort by the Women with Disabilities Center and all of the collaborating partners. Our goal was to provide radiographers with advanced knowledge and tools with which to conduct effective screening mammograms for women with a variety of disabling conditions. We piloted the curriculum, taught by 3 mammographers and a woman with a disability at two academic medical centers and one community hospital. The evaluations of the sessions were all highly positive. The attendees from each session requested that more information on positioning be included.

Five months later, the revised curriculum was presented at the Lynn Sage Breast Center of Northwestern Memorial Hospital. Forty mammography staff from 20 different

medical facilities in the Chicago area were present. The session was offered as a 5 credit continuing education program through the Illinois Emergency Management Agency. The program components focused on: skills for modifying mammography positions, diversity of challenges based on differences of disability, effective communication skills for working with the disability community and understanding barriers to screenings for women with disabilities.

A unique aspect of the presentation was a panel of eight women with disabilities. These women represented the gamut of physical conditions from limb loss to brain injury. The women shared their stories of having mammograms and held an open, rewarding dialogue with the mammographers as to how they could best work with them.

The session was extremely popular and the evaluations were very positive from all attendees. This program assisted mammographers who experience women with diverse disabilities. We were able to successfully raise awareness of specific needs and successful strategies and promote the adoption of best practices in screening for women with disabilities. By improving screening rates through education and advocacy and improving the quality of the screening, we believe we can remove significant barriers to preventive health practices among women with disabilities.

**RESOURCEFUL WOMAN**  
Women with Disabilities Striving toward Health and Self-Determination

**Breast Health for Women with Disabilities - A PROACTIVE APPROACH**

By MARY MARGARET SHARP-PLUCCI

Pink ribbons represent breast cancer and the Women with Disabilities Center at the Rehabilitation Institute of Chicago (RIC) has been aglow in pink ribbons these past few months. The Center is taking the lead in making breast health a priority among women with physical disabilities by encouraging women to be proactive about performing regular self-exams and scheduling annual mammograms.

Approximately one in eight women in the U.S. will develop breast cancer at some point in her life. Women with disabilities are no different.

Guidelines recommend that all women have yearly mammograms starting at age 40 but only 61% of U.S. women aged 40 and older had one within the past year. The screening rates are about the same for women with and without disabilities. In spite of this, women with disabilities tend

differences have been found in the adequacy of follow-up services and mortality rates. These observations are supported by new research published in the *Annals of Internal Medicine*: Not only did women with disabilities have higher breast cancer mortality rates in this study, but they were less likely to undergo standard therapy after breast-conserving surgery than other women.

Regular mammography screenings are a woman's best chance for detecting breast cancer early. Increasing numbers of women are diagnosed in the early stages of the disease as women adhere to screening guidelines and the sophistication of imaging technology continues to improve. Mammography screenings can significantly improve a woman's chances of survival when coupled with new therapies and advanced surgical techniques. Actor-director Woody Allen is known for saying "80% of success is showing up." When it comes

Our Women with Disabilities Center was one of three national sites selected to participate in a Centers for Disease Control (CDC) project designed to increase the awareness of breast cancer prevention among women with physical disabilities. Over the years, the

*continued on page 9*

Breast cancer was just another obstacle I had to fight.

The Women with Disability Center at RIC publication.. If you would like to be added to the Women with Disabilities Center's mailing list, please email [kbullock@ric.org](mailto:kbullock@ric.org).

# Chicago Area Accessible Mammography Centers

(Partial List)

Courtesy of the Women with Disabilities Center at RIC

## Chicago Area Accessible Mammography Centers

SELF IDENTIFIED (This list is not comprehensive)

**(Near North)**

Northwestern Memorial Hospital  
Lynn Sage Comprehensive  
Breast Cancer Center  
251 East Huron  
Galter Pavilion – 13th Floor  
Chicago, IL 60611  
Phone: 312.926.5522

**(Near West)**

Rush University Medical Center  
Rush Breast Imaging Center  
Professional Office Building  
1725 West Harrison Street  
Chicago, IL 60612  
Phone: 312.563.3498

**(North Sub)**

Rush North Shore Hospital  
The Centre for Women's Health  
Kenton Building  
9700 N. Kenton  
Skokie, IL 60076  
Phone: 847.677.1400

**(West Sub)**

Little Company of Mary  
Breast Health Center  
2800 W. 95th Street  
Evergreen Park, IL 60805  
Phone: 708.229.5527

**(South Sub)**

Advocate Christ Medical Center  
4440 W. 95th Street  
Oak Lawn, IL 60453  
Phone: 1-800.970.2778

**(Near West)**

Mt. Sinai Hospital  
California Ave at 15th Street  
Chicago, IL 60608  
Phone: 773.542.2000

**(Near West)**

John H. Stroger, Jr. Hospital  
(Cook County Hospital)  
1969 West Ogden Avenue  
Chicago, IL  
Phone: 312.864.6000

**(West Sub)**

Rush Oak Park Hospital  
Radiology/Mammography  
520 S. Maple Avenue  
Oak Park, IL 60304  
Phone: 708.660.6266

**(Near West)**

University of IL Medical Center  
811 South Paulina  
Chicago, IL 60612  
Phone: 312.996.0267

**(Near West Sub)**

Loyola University Health System  
2160 S. First Avenue  
Maywood, IL 60153  
Phone: 708.216.8563

**(North)**

Breast Center of St. Francis Hospital  
800 W. Austin  
Evanston, IL  
St. Francis Hospital & Health Center  
12935 S. Gregory  
Blue Island, IL 60406  
Phone: 708.597.2000

**(Far South)**

Ingalls Hospital  
One Ingalls Drive  
(156th Street off Wood St.)  
Harvey, IL 60426  
Phone: 708.333.2300

**(Western Sub)**

Delnor Community Health System  
Center for Breast Health  
300 N. Randall Road  
Geneva, IL

**(Far North Sub)**

YWCA Lake County  
ENCORE Plus Program  
2133 Belvidere Road  
Waukegan, IL

**(City South)**

University of Chicago Hospital  
Radiology  
5758 South Maryland  
Chicago, IL 60637  
Phone: 773.834.7032

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The RIC Women with Disabilities Center



Rehabilitation Institute of Chicago



## Getting It Right

by Judy Panko Reis, MA , MS

Director of The RIC's Women with Disabilities Center

As I read the first class tour de force, *More Than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities*, I couldn't stop thinking about Monica, whose recent experience with the health care system left me shocked. Monica's story underscores the urgent need this book advances—improving the quality of health care for people with disabilities.

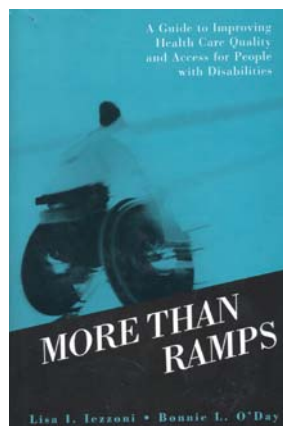
When admitted to the hospital for an infected pressure sore on her left ankle, Monica encountered, as she had in the past, clinicians who were flustered by her use of a wheelchair. As the physician was cleaning the wound she told him it hurt. "This shouldn't hurt you", he said. "You're paralyzed and can't feel it." Taken aback, she asked how her wound looked and was told, "It needs amputation." Perplexed by the vague reference, she asked what needed amputation. "Your leg," he replied. Stunned by the news and his callous manner (she had expected antibiotics and nursing care), Monica became agitated and sad. Grief turned to disbelief when the physician said, "I don't know why you are so upset; you're paralyzed and can't walk anyway."

Monica's problems with clinician communications are a startling, but too often experienced example that could have been included in this book. Its many graphs, charts, photos and patient interviews document the health care barriers confronted by persons with disabilities and provide suggestions for improvement. It is an engaging, solution-based book that succeeds in translating the history and urgency of the need for high quality patient centered care to adults with physical and sensory disabilities into achievable accessible techniques in the primary care setting.

The authors, Lisa I. Iezzoni, M.D., MSc of Harvard Medical School, and Bonnie O'Day, Ph.D, currently at Mathematica Policy Research, are health care policy researchers who each live with disabilities, Dr. Iezzoni with mobility impairments who uses a motorized scooter and Dr. O'Day who has low vision and uses a white cane. Their work is singular in its ease in moving beyond analysis to building a convincing case for applying specific remedies to the described challenges. What's more, they show how the anticipation and implementation of accessible strategies can improve care for patients while also offering long-term financial benefits to providers and clinics.

The triple layered text opens with Part I, a rigorous description of the development of disability paradigms and policies that helped define the population. The authors deliver a history of health care access for Americans with sensory and physical disabilities that peels through the patina of everyday health insurance definitions, laws and social practices to expose the roots of policy biases, disincentives and structural obstacles that prevent people with disabilities from living independently in the community, and from receiving quality health care in the primary care setting. The primacy of the Institute of Medicine's 2001 recommendations for quality health care is underscored with a strong emphasis for "patient centeredness" of people with disabilities. Embracing a universal design mindset, the authors advocate for the creation of patient centered health care systems that respect patient values and perspectives and can anticipate "the physical, sensory, cognitive, emotional and spiritual needs of all persons regardless of their abilities or disabilities."

The call for immediate access solutions is well-founded, given that today's health care delivery system is designed to provide acute care, leaving it unprepared to care for growing numbers of baby boomers aging with chronic conditions which leave them with impaired vision, hearing and physical functioning. The analysis suggests that if the U. S. health care delivery system is not restructured to provide truly accessible patient centered care, boomer's' access needs will surely overburden an already strained system in the next two decades. (cont. on p. 12)



Available for checkout in the Donnelley Family Disability Ethics Library in the South Mezzanine.

**Getting It Right, cont. from p. 9)**

When it comes to identifying the range of subtle and overt health care barriers people with disabilities face daily, ranging from insurance disincentives and provider misconceptions to the impact of the scarcity of sign language interpreters, accessible scripting and accessible exam tables, scales, and screening technologies, there are few, if any, accounts that tackle the spectrum with the depth and scope of Part II of this book.



An adjustable exam table which lowers to wheelchair seat height, making transfers easier and safer for both the patient and the medical staff. Picture not copyrighted.

The nuances of financial, attitudinal and environmental obstacles including, among others, hospital administration, transportation, housing, and personal assistance, are described in a narrative that deftly blends quantitative analysis from national surveys and governmental policies with vivid patient narratives. The style brings to life the dehumanizing, difficult and dangerous health care experiences of patients with sensory and physical limitations.

The final section of the book focuses on circumventing barriers with the goal of improving health outcomes. It addresses the relevance and limitations of the Americans with Disabilities Act in the health care setting, health benefits of proper architectural and equipment design, techniques for applying universal design principles to help improve the quality of health care for patients who live with hearing, vision and physical impairments, and urges the inclusion of people with various disabilities in the design process. With an endorsement of patient clinician collaboration and formalized self management programs and trainings for persons with disabilities, it affirms the primacy of patient expertise in living with a disability by fostering an approach that recognizes the strength of clinician and patient in partnering together to

define optimal health goals and identify solutions to health concerns.

Linking effective patient-clinician communications to optimal health care, the authors discuss assistive technologies, recommend specific steps to improve these communications and stress the importance of training programs to educate clinicians on the lived experiences of persons with disabilities.

The book invites us all proactively to counter trends showing rising rates of obesity and its many disabling effects by participating in the creation of person centered communities that promote healthy living and universal access in the built environment. Tools and resources to support this effort and the authors' plethora of recommendations for the creation of truly accessible patient centered health care systems are included in the book's four extensive appendices.

Among the many fascinating discussions that stud this book what is most impressive are the segments elucidating provider-patient etiquette, what used to be called "bedside manner" and communication barriers. Monica's experience could have been substantially ameliorated had the doctor tried figuratively to put himself in the patient's seat-to view the medical interaction from her perspective and to give her credit for her own experience "that hurts". Iezzoni and O'Day have written a work that should be required reading for all medical students, clinicians and health care providers who will be better prepared for "getting it right".



Whitepaper written by Judy Panko Reis, MA, MS, Director of RIC's Women with Disabilities Center, Mary Lou Breslin, MA, Senior Policy Advisor, Disability Rights Education and Defense Fund, Lisa I. Iezzoni, M.D., MSc, Harvard Medical School, and Kristi L. Kirschner, M.D., Director of RIC's Donnelley Family Disability Ethics Program. Published by RIC and available at [http://www.tvworldwide.com/events/hhs/041206/PPT/RIC\\_whitepaperfinal82704.pdf](http://www.tvworldwide.com/events/hhs/041206/PPT/RIC_whitepaperfinal82704.pdf)

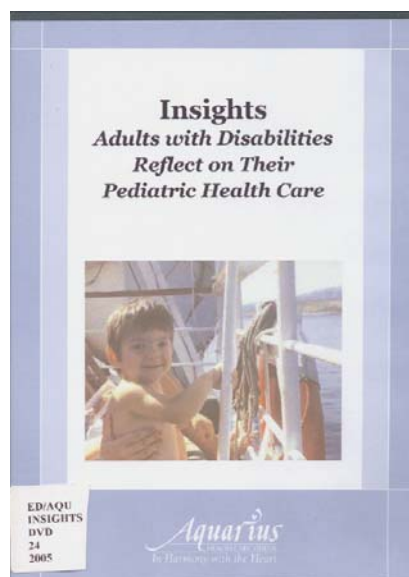
## Ethics Resources for RIC Staff

Currently located on the South Mezzanine, the Donnelley Family Disability Ethics Program houses a library, periodical section, and a VHS/DVD collection.

**Library.** The Ethics Library now houses over 700 volumes. The library incorporates a broad range of works on biomedical ethics, disability rights, and narratives of those living with a disability. Staff may check out three items (three books, three videos/DVDs, or a combination of the two) for two weeks, and may renew items for an additional two weeks. We also invite you to utilize our library as a quiet place to read and reflect.

**Periodicals.** We currently subscribe to twenty-four periodicals. Among these are *Archives of Physical Medicine and Rehabilitation*, *Journal of Disability Policy Studies*, *The Journal of Clinical Ethics*, *The Hastings Center Report*, *Disability and Society*, and *the American Journal of Bioethics*.

**Film Library.** Our film library has over 200 videos/DVDs on a variety of ethical issues regarding disability. These may be checked out.



This video was produced by Donnelley Family Disability Ethics consultant Teresa A. Savage, PhD, RN, together with Beverley Tann, staff nurse at RIC and Senior Scholars Sheila Hickey, Diane Dudas Sheehan, and Janet Simpson. This is one example of a film which can be checked out from our Film Library.

**Film Series.** Once each month, we show a film from our library collection. The films are shown in the Ethics Conference Room on the South Mezzanine. The films are always shown at noon, but the day varies to enable a variety of staff to attend. If you have any questions regarding the film series, please contact Carmen A. Cicchetti at 312.238.1119 or at [ccicchetti@ric.org](mailto:ccicchetti@ric.org)

Fri., Feb. 27th: **Shameless: The Art of Disability**

Wed., Mar. 25th: **The Cyborg Revolution: Advances in Brain/Body Control**

Mon., April 27th: **No Bigger Than A Minute**

**Educational Seminars.** Each month the Donnelley Family Disability Ethics Staff conduct an educational seminar for RIC staff. If you would like us to conduct an educational seminar on ethical issues for your staff, please contact Dr. Debjani Mukherjee, Ph.D., at 312.238.1885 or at [dmukherjee@ric.org](mailto:dmukherjee@ric.org)

**Ethics Scholars Program.** The Ethics Scholars Program is an 11 month program which provides training and professional development in ethics. The program is available free of charge to all members of the RIC community. Information on this program is available on our webpage at <http://www.ric.org/conditions/community/ethics/Education.aspx>

**Ethics Consultations.** Ethics consultations are available upon request by calling 312-238-1119.

**Contributions** to the Donnelley Family Disability Ethics Program enables us to promote our mission, which includes educating health care professionals about the health care needs of people with disabilities.

RIC relies on its generous donors to sustain and grow the Disability Ethics Program's education, research, hospital-based services, and community activities that increase awareness of disability and ethics. This Program not only serves as an important resource for our patients, but staff, healthcare professionals and policy makers as well. Contributions can be made online by going to <http://www.ric.org/foundation/donate/online/index.aspx> There you can designate your donation to the Donnelley Family Disability Ethics Program by selecting "Other" and typing in the name of the Program. You may also contact the Philanthropy Office directly by calling 312-238-6013. Thank you for your support!

### Donnelley Family Disability Ethics Staff

**Kristi L. Kirschner, MD**  
Director  
312-238-4744

Debjani Mukherjee, PhD  
Associate Director  
312.238.1885

Rebecca Brashler, LSW  
Director, Care Management  
& Family Support  
312.238.1312

Teresa A Savage, PhD, RN  
Consultant  
312.238.1884

Teresa Moro, AM, LSW  
Clinical Educator  
312.238.1884

Carmen A. Cicchetti, M.Ed, MA  
Business Support Manager  
Newsletter Editor  
312.238.1119

Jennifer Zolp, RN  
Newsletter Copy Ed.  
312.238.2212