Ethical Considerations in the Delivery of Health Care and Rehabilitation Services to People with Disabilities
• **Lex Frieden**, Professor, Biomedical Informatics & Rehabilitation, University of Texas Health Science Center at Houston

• Professor, Dept of Physical Medicine & Rehabilitation at Baylor College of Medicine

• Director, ILRU (Independent Living Research Utilization) program at TIRR Memorial Hermann

• Convener, National Advisory Board for Improving Health Care Services for Seniors and People with Disabilities

lex.frieden@uth.tmc.edu
President George H.W. Bush
July 26, 1990
In the past 20 years has any cultural, social or legislative change affected your life more than the ADA?
Respondents with Disability (N = 609)

People with disabilities believe that ADA has been the most significant social, cultural or legislative influence on their lives in the past 20 years.

Yes (N=214) 35%
No (N=395) 65%
The ADA’s greatest impact has been improvements in access to public accommodations.

% of Respondents Indicating Areas of Greatest ADA Impact
N = 870
Employment, access to health care and access to community and independent living were ranked as the highest areas of future ADA impact.

% of Respondents Indicating Areas of Greatest ADA Impact
2010-2020
N = 870
Current Reality
• Today there are 56.7 Million People with Disabilities.
• There are 75 Million Baby Boomers.
• Half the Baby Boomers will have a disability by 2020.

• one out of five Americans has a disability.
Eighty-one point nine percent (81.9%) of persons with a disability are unemployed: compared to 36.1 percent (36.1%) of persons without a disability.


Twenty-seven point nine percent (27.9%) of adults with disabilities are living below the poverty line: compared to 12.5 percent (12.5%) of persons without a disability.

US Census Bureau, 2011

An estimated fifty-five percent (55%) of people with disabilities and seniors do not have needed access to primary health care or to preventative health care services.

WHO, 2010
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WHO, 2010
Disparities in Health Care

• Pap smears: 69% of adult women with disability vs. 77% women without disability

• Breast exams, Mammograms: 50% women with disability aged > 50 years vs. 56% women without disability of same age

• Providers: failure to mention or inquire about diet, exercise, pain, sleep, changes in functional status

• Non-elderly disabled Medicare beneficiaries more likely to have lower income & difficulties accessing care than elderly counterparts

US DHHS Office on Disability
Opinions about Service Providers

• Disability or economic status prevented consumers from accessing preferred service providers
• Had difficulties in accessing service provider's office
• Had difficulties in accessing equipment
• Had difficulties in accessing washroom
• Service provider “did not listen”
• Service provider “just listened”
• Services received were regarded as inadequate
Framing Contemporary Solutions
Report Findings: Access To Quality Health Services and Disability - A Companion To Healthy People 2010

- Many people reported that they had difficulty finding a service provider who “understands my disability.”

- Many service providers lack the training to meet the full range of needs presented by an individual with particular disabling conditions, much less to evaluate and treat that individual in a culturally sensitive and competent manner.
• Existing health care and wellness systems are not sufficiently responsive to the needs of persons with disabilities. As a result, access to rehabilitation, education, prevention, screening, diagnosis, treatment, and wellness services can be limited, incomplete, or misdirected.

• Clinics and services are often inaccessible to people with physical disabilities. More than discomfort, the result is often incomplete and potentially inaccurate examinations.
Many people in the United States experience physical limitations or impairments that might require accommodations such as accessible testing facilities, clinical exam tables or weight scales.

Many people experience sensory limitations or impairments that might require Sign Language interpreters, or print materials in accessible formats such as Braille or large print in order to receive effective rehabilitation and healthcare.
Food for Thought
• Be sure that the facilities to which you refer patients or clients for other services are accessible.

• Understand that not having access to work, school, health care, or fun things to do can cause more problems than a disability itself.

• Engage informally with consumers in social, recreational, cultural, and community improvement activities.

• Address the needs of the whole person, not just the disability.
• Be exceptionally attentive to concerns of pain, depression, job pressures, smoking, drug and alcohol use.

• Always be sensitive and allow for the extra time it might take a person with a disability to speak or act.

• *Ask the person* with a disability if he or she needs any help. *Do not assume* help is needed. Communicate!
Ethical Principles

- **Respect for autonomy** -- the consumer or patient has the right to refuse or choose their treatment.

- **Beneficence** -- a practitioner should act in the best interest of the consumer or patient

- **Non-malfeasance** -- first, do no harm.
Ethical Principles

• **Justice** -- managing the distribution of scarce resources, and deciding who gets what treatment or service (fairness and equality).

• **Respect for persons** -- the consumer or patient has the right to be treated with dignity.

• **Truthfulness and honesty** -- the consumer or patient has the right to informed consent.
Ethical Dilemmas in Rehabilitation
Ethical Dilemmas

- Concurring with a consumer's decision to reside with aging parents conflicts with preparing the consumer to live independently outside a sheltered and protected environment.

- Supporting a consumer's choice of services conflicts with providing services that can increase the consumer's potential.
Ethical Dilemmas

• Providing an employer with all requested consumer information conflicts with serving as an advocate for the consumer in the job placement process.

• Withholding information about a consumer's medical condition from other professionals at the consumer's request conflicts with making appropriate referrals for necessary medical services.
Ethical Dilemmas

- Informing a consumer about a fatal disease so the consumer can plan for the future conflicts with not disclosing distressful medical information to a consumer whose physician has not revealed or explained the disease.

- Funding a high-cost service such as surgery to prolong a consumer's productive life conflicts with providing other services to large numbers of other consumers with the same funds.
Ethical Dilemmas

• Providing a consumer with private transportation conflicts with requiring the consumer become more self-reliant by using integrated, low-cost public transportation.

• Returning a consumer to work at the insurance carrier's request conflicts with providing placement services when the consumer is job ready.
Ethical Dilemmas

• Providing vocational services to a certain consumer conflicts with adhering to order of selection criteria of the agency.

• Closing a consumer's case as a homemaker in accordance with the rehabilitation team's decision conflicts with providing further services to enhance employment potential.
Ethical Dilemmas in Services to Veterans
Ethical Dilemmas – Veterans

•*Managers* worried about how to distribute resources fairly among the different components of the facility and what kind of process to follow in doing this.

•*Clinicians* worried about providing high quality care with limited resources and balancing duty to patients with the obligation to be stewards of VA resources.
Ethical Dilemmas – Veterans

- *Ethics committee chairs* were most concerned with improving end-of-life care and ensuring that patient preferences were honored.

- *Patients* had as their top priorities receiving respectful and caring treatment from all staff and improving service quality.
Ethical Dilemmas in Health Care
Ethical Dilemmas in Health Care

• Triage and rationing strategies during emergencies such as pandemic flu outbreaks conflict with rules regarding the code of preserving life by all means possible.

• Withholding treatment in order to be responsive to the DNR orders conflicts with the code of providing whatever services are necessary to protect and preserve life.
Ethical Dilemmas in Health Care

• Euthanizing people with disabilities in order to preserve food and other necessary staples for the benefit of healthier members of a tribe or society conflicts with the code of preserving and protecting human life.

• Euthanizing people with disabilities to make them free of pain and suffering (from the perspective of others) conflicts with the ethical principle of autonomy.
Ethical Dilemmas in Health Care

• Using people with disabilities as human shields conflicts with the ethical principles of equality and justice.

• The use of children who have Down’s syndrome or those who are autistic by for target practice by military trainees in order to prepare for defending themselves conflicts with the ethical requirement to preserve and protect life.
On The Horizon

• New Medical Equipment and Devices
• Assistive Technology
• Revised ADA Guidelines
• Home and Community-Based Services
• Managed Care and Medical Homes
• TeleHealth
• Emphasis on Services to Veterans
A Call To Action
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• Support and promote services that allow individuals to participate in social, economic, educational and recreational activities

• Realize the synergy of a continuum of services and supports

• Make long-term services and supports a priority in health care and rehabilitation
A Call To Action

• Expand options for follow-up rehabilitation, training, transportation, housing, community-based personal assistance services, assistive technology, community participation, volunteerism and employment

• Resolve ethical dilemmas through resource development, education and training, and improved service delivery
A Call To Action

• Engage Users and Consumers in Meaningful and Open Dialogue
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• *Recruit People with Disabilities for Service on Boards and Advisory Committees*
A Call To Action

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• Recruit People with Disabilities for Service on Boards and Advisory Committees

• *Respect the fact that People with Disabilities are ultimately responsible for making decisions that affect their own lives*
For ADA Technical Assistance Contact 1-800-949-4232