

Approaches to Training Healthcare Providers on Working with Patients with Disabilities

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Approaches to Training Healthcare Providers on Working with Patients with Disabilities

Objectives

1. Describe approaches to “making the case” for training health care providers
2. Address knowledge, attitudes and skills important in training health care providers about care of patients with disabilities
3. Discuss methods of designing training programs for providers
4. Discuss steps for implementing provider trainings at various institutions (health care professions’ schools, organizations, societies, etc.)
5. Describe elements of successful training programs for health care professionals

Background / Making the Case



Epidemiology of Disability

Prevalence

- **~ 20% of population over the age of 5 has a disability**
- **54 – 60 million people in the US have a disability; 1 billion worldwide live with a disability**
- **Prevalence of disability increases with age but occurs across the lifespan** (McNeil, 1993; CDC, 2009)
 - 13.9% of children (< 18 years of age)
 - 11.0% of 18 - 44 year olds
 - 23.9% of 45 - 64 year olds
 - 51.8% of those \geq 65 years of age
 - 44.6% of 65 - 74 year olds
 - 63.7% of 75 – 84 year olds
 - 84.2% of \geq 85 year olds

Definitions and Characteristics of Disability

Americans with Disabilities Act (ADA) Definition of Disability:

A mental and/or physical impairment that has an effect on the individual's ability to carry out major life activities.

The impairment must be substantial, adverse and long-term.

Definition and Characteristics of Disability...

WHO' s Definition of Disability:

“Disability” is an umbrella term for impairments, activity limitations or participation restrictions

Focus moved away from “consequence on disease” to one on health and factors that affect health

A person' s functioning / disability is seen as a dynamic interaction between health conditions (diseases, disorders, injuries, etc.) and contextual factors (personal and environmental factors) that affect health.

WHO (2000). International classification of functioning, disability and health. WHO: Geneva.



Definition and Characteristics of Disability...

Another View of Disability

“Disability is a universal experience that affects nearly everyone without exception at sometime in their lives.”

Kirschner, K. & Curry, R. (2009). Educating health care professionals to care for patients with Disabilities. *JAMA*, 302(12), 1334-1335.



Significance of Definitions of Disability

The definitions and the view of disability that we have...

- **Determine who is eligible for services and what services are allowed**
- **Affect our attitudes, views, and perceptions of people with disabilities**
- **Influence how we interact with and treat people with disabilities in all education, clinical practice, and community sites and settings**
- **Influence how we teach others about disability-related issues**

Characteristics of Disabilities

- **Disabilities vary in severity**
 - **Very mild (inconvenience)**
 - **Moderate (interfere with some activities)**
 - **Severe (assistance needed for IADLs, ADLs)**
 - **Very severe (technology needed for survival)**
- **Disabilities vary in type**
 - **Physical disabilities**
 - **Sensory (vision and hearing) disabilities**
 - **Psychiatric mental health disabilities**
 - **Cognitive/intellectual disabilities**
 - **Communication disabilities**

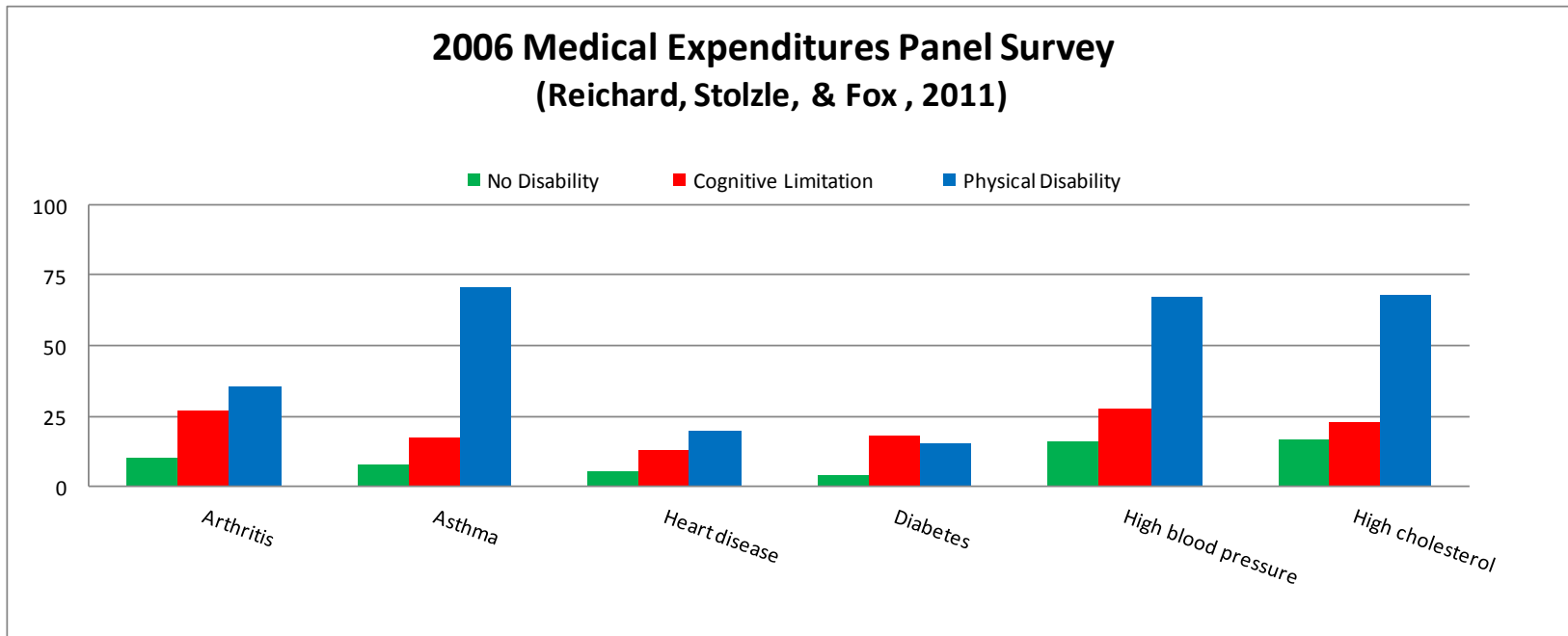
Characteristics of Disabilities...

- **Disabilities vary in visibility**
 - **Not at all visible to others**
 - **Visible to informed others**
 - **Visible to all**
- **Population of persons with disabilities (PWDs) is increasing**
 - **Advances in health care and survival of people with disabilities across the lifespan (VLBW babies, adults who are chronically critically ill, etc.)**
 - **Increase in number of people with chronic disease**
 - **Increased survival of those with trauma**
 - **Increased number of elderly and frail elderly**

Common among People with Disabilities

- **Difficulty obtaining health care and screening**
- **Negative health care encounters with physicians, nurses, and other health care professionals (HCPs)**
 - **Ineffective communication between HCPs and persons with disabilities**
 - **Failure of HCPs to communicate directly with persons with disabilities**
 - **Assumptions by HCPs that QOL of persons with disabilities is poor**
 - **Failure of HCPs to recognize experience, knowledge and expertise of PWDs about own health and disability**
 - **Belief of HCPs that PWDs cannot be healthy**
- **Higher incidence of health disparities than those without disabilities**

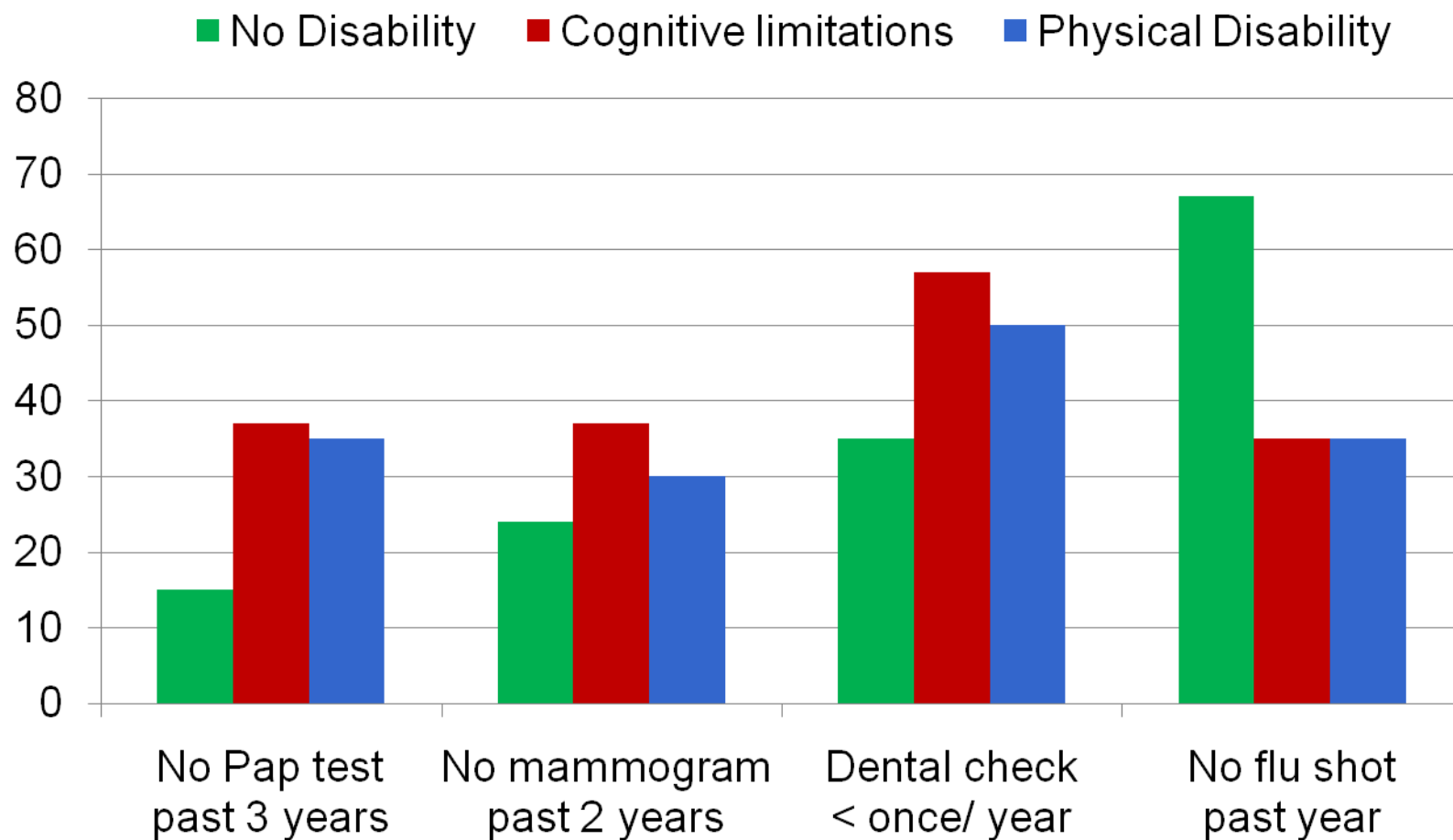
Health Disparities: National Statistics



Preventive Screenings: National Statistics

2006 Medical Expenditures Panel Survey

(Reichard, Stolzle, & Fox, 2011)



Minorities and Disabilities

- According to a recent report (Drum, Taitano & Horner-Johnson, 2011), people from minority racial/ethnic groups who also have disabilities confront an enormous **health disparity amplifying phenomenon**

Percent of Adults reporting Fair or Poor Health Status

	No Disability	Disability
Hispanic	19	50
Native American	9	52
African American	11	50
Asian American	6	38

- Overall, adults with a disability were less likely to report excellent or very good health (27.2% vs. 60.2%), and were more likely to report being in fair or poor health (40.3% vs. 9.9) than adults without disabilities.

Health Challenges of People with Disabilities

- People with disabilities share many of the same challenges as those without disabilities when it comes to their own health and well-being.
- Lack of preventive care – health care, preventive health screening and dental services
- Children, youth and adults with disabilities may require a broad range of services
- Greatly increased risk of all types of abuse in people with all types of disabilities and all ages
- Increased risk of secondary conditions



What are Secondary Conditions?

- **Physical, medical, cognitive, emotional, or psychosocial conditions that can occur as a result of having a primary disabling condition (IOM, 1991)**
- **Secondary conditions can include disorders associated with aging, but may occur at a younger age in people with a primary disabling condition.**
- **Secondary conditions cause adverse outcomes in health, wellness, community participation, and quality of life (Hough, 1999)**
- **Some disabilities may lower the threshold to an array of secondary conditions.**
 - **87% of persons with a disability report at least one secondary condition vs 49% of those people without a disability (Kinne et al., 2004)**

Common Secondary Conditions

- **Depression**
- **Urinary tract infections**
- **Unwanted weight gain**
- **Chronic pain**
- **Excessive Fatigue**
- **Respiratory Infections**
- **Hypertension**
- **Skin Lesions**
- **Contractures**
- **Social isolation**
- **Osteoporosis**
- **Fractures**

(Simeonsson & McDevitt, 1999)

Secondary Conditions

- **Secondary conditions in all groups can result if special health care needs are not identified and treated promptly**
- **Early and continuous screening can reduce the risk of secondary conditions and improve health outcomes**
- **Appropriate health care, screening and prevention of secondary conditions can maintain well-being and quality of life of people with disabilities**



Recommendations to Improve Health of People with Disabilities

Two Surgeon General reports (2002, 2005), one Institute of Medicine Report (2007), the National Council on Disability Report (2009), and the WHO World Report on Disability (2011) recommended several key actions to improve the health of people with disabilities:

1. Improve public recognition that people with disabilities can live long, healthy and productive lives and reduce stigma and discrimination;
2. **Improve knowledge, skills and attitudes of health care providers to improve care;**
3. Improve accessibility of health care, including insurance, facilities, equipment, transportation;
4. Improve opportunities for health promotion, safety and wellbeing;
5. Improve data on disability populations, and research on disability-related health disparities and interventions.

(Fox & Courtney-Long, 2012)



Without training, healthcare providers...

- **Tend to underestimate the abilities of patients with disabilities.**
- **Grossly underestimate the quality of life of patients with disabilities.**
- **Minimize the patient's capacity to contribute to their own care.**
- **Minimize the extent and importance of the patient's expertise in own condition.**

Health of Persons with Disabilities (PWDs): What to teach

- Disability ≠ poor health.
- PWDs have healthcare needs like everyone.
- PWDs need healthcare professionals who really listen to, communicate with, and respect them.
- PWDs need healthcare professionals who treat *all* of their health needs.
- PWDs need to be treated as partners in care process.

Making the Case For Addressing Disability in HCPs' Curricula

- **Help decision makers understand the nature and prevalence of disability**
- **Address resonance with patient-centered care and medical home models**
- **Explore disability in context of cultural competence or diversity**
- **Addressing disability through patient-centered care and medical home approach improves care for all**

Medical Home

- **Provides primary care that is accessible, continuous, comprehensive, patient (or family) centered, coordinated, compassionate, and culturally effective.**
- **In a medical home, healthcare providers partner with the patient and his/her family to assure that all of the medical and non-medical needs of the patient are met.**
- **Coordination of care is key to quality care of patients with disabilities and underlying concept of medical home approach.**

Medical Home for PWDs

- **Medical home approach is considered gold standard for patient care**
- **Medical home approach exquisitely meets the needs of patients with disabilities.**
- **Medical home introduces health care providers to the topic of children with special health care needs and adults with disabilities and coordination of care.**

Cultural Competence

- **Health care training programs increasingly add content to curricula to prepare culturally competent providers**
- **Attempts are being made to expose students to “diverse” patient populations**
- **Disability should be considered among cultures that can influence an individual’s perspective of health and healthcare**



Desired Outcomes of Training of Health Care Professionals

Realms of Desired Outcomes

- **Knowledge**
- **Attitudes**
- **Skills**

Desired Outcomes in the Knowledge Realm

- **Be familiar with disabling conditions and their associated / secondary medical conditions**
- **Acknowledge “narrow margins of health”**
- **Be familiar with assistive technology (including augmentative communication devices) and associated prescriptions**
- **Recognize the patient as an important source of information**
- **Understand legal and consent issues when patients have cognitive disabilities**

Desired Outcomes in the Knowledge Realm...

- **Be aware of appropriate and preferred language (e.g., “person first”)**
- **Understand alternative positioning needs during physical examinations**
- **Recognize accessibility issues in the clinical environment**
- **Be familiar with social service and health care financing systems and issues**
- **Understand the complex interplay between disability and health**

Desired Outcomes in the Attitudes Realm

- **Acknowledge interdisciplinary team approaches to address the complex interplay between disability and health**
- **Accept that some people with disabilities might approach the encounter with mistrust because of previous negative experiences with HCP**
- **Recognize sexuality and reproductive health of people with disabilities**

Desired Outcomes in the Attitudes Realm...

- **Recognize one's own attitudes toward persons with disabilities, including one's own cultural influences**
- **Support partnerships with patients and respect their autonomy (e.g., avoid “infantilization”)**
- **Appreciate the importance that persons with disabilities place on preserving function and maintaining their lifestyles**

Disability Cultural Values - Gill

- 1. an acceptance of human differences,**
- 2. a matter-of-fact orientation toward helping and being helped,**
- 3. a tolerance for lack of resolution or cure, and dealing with the unpredictable,**
- 4. a sense of humor about disability,**
- 5. skill in managing multiple problems,**
- 6. flexible, adaptive, resourceful approach to tasks and problems**

The Challenge of Changing Attitudes

- **Health care students are often taught by faculty with unfavorable attitudes regarding disability**
- **Change in explicit attitudes isn't enough; there must be change in implicit attitudes**

Students' exposure to persons with disabilities should include (although not exclusively) strong positive exemplars

Desired Outcomes in the Skills Realm

- **Be able to recognize acute and chronic issues unrelated to the disability**
- **Prevent co-morbid / secondary conditions**
- **Use proper etiquette (e.g., sit at eye level; announce presence with patient is visually impaired)**
- **Ask patients about their preferred method of communication**
- **Support the use of augmentative communication devices/strategies**
- **Use proper positioning techniques**
- **Manage clinical interview to ensure patient participation in presence of caregivers**

Strategies



Today you will learn...

- **That by including disability in healthcare training curricula, people with disabilities are more likely to achieve health equity.**
- **That people with disabilities are extremely effective as teachers in disability curricula.**
- **That actors feigning disability are not credible.**
- **Different approaches to disability education.**
- **How to overcome common challenges in disability training.**
- **How to start a disability training program.**

Important to use *actual* PWD

- **Actors feigning disability are not credible faking:**
 - **Atrophied muscles**
 - **Deafness**
 - **Blindness**
 - **Contractures**
 - **Spasticity**
 - **Ptyalism/drooling**
 - **Poor head control**
 - **Dysarthric/slurred speech**
 - **Devices used for communication**
 - **Communication patterns often used by a person with an intellectual disability**

Home Visits

- **Opportunity to meet informally with PWD in their home**
- **Challenge assumptions and limiting attitudes**
- **Appreciate the value of preserving function and lifestyle**
- **Witness the PWD as an expert in their own condition and health**



Didactic Instruction

- **Address aspects of knowledge domain**
- **Appreciation of prevalence and range of disability, and abuse risk**
- **Understanding of health and healthcare disparity**
- **Emphasis on preventing secondary conditions and improving quality of life**
- **Guidance on disability etiquette**

Patient Panel

- **PWDs can talk about healthcare experiences**
- **PWD can list qualities of ideal healthcare provider**
- **Opportunity to present variety of patients with different life experiences and functional limitations**
- ***Every patient is unique***



PWD as Standardized Patients (SP)

A very effective way to teach students about PWD

- **Controlled but realistic clinical exposure to patients with disabilities**
- **Scenarios can be tailored to focus on communication issues, medical complexity, interplay between health and disability, etc.**
- **Direct debriefing by the person with a disability**
- **Allows student to see individual with a disability in a teacher role**



Formative and Summative Exam

Use of PWD as model patient and OSCE encounters to teach:

- **Transfer skills**
- **Communication skills**
- **Disability and associated conditions**
- **Support partnerships with patients**
 - **Respect their viewpoint**
- **Recognize accessibility issues**
- **Opportunity to evaluate students**



Clinical Experience

- **Attendings and preceptors = Positive role models essential**
- **Build comfort and clinical skill in clinical environment**
- **Experience with assistive technology, alternative positioning**
- **Incorporating family member or aide in exam**
- **Acknowledge disability but keep perspective**

Community Service

- **Provide opportunities for students to interact with people in athletic leagues or local social or advocacy organizations to interact informally with PWD and provide a service**
 - **e.g., provide health education to PWD, physicals for hippotherapy, etc.**



Benefits

- **Understanding disability ≠ poor health**
 - Concepts of thinner margin of health, secondary conditions
- **Authenticity: Actors without disabilities...**
 - Cannot mimic
 - May reinforce negative stereotypes especially off script
- **Recognition of patient expertise about own condition**
 - Rich lives, jobs, families, responsibilities, future plans
- **Provides special teachable moments**
 - Communication devices, transferring patients to exam tables, talking with caregivers present

Challenges

- **Evaluation can be tricky**
 - Consistency - script vs. telling own story
 - Lack of consensus regarding competencies that are observable
 - SPs who evaluate must be trained
- **Attendance of PWD**
 - Recruitment of people with requisite skills may already have full time employment
 - Stamina
 - Fluctuating health status
 - Transportation difficulties

Starting a Program

- **Funding:** Grants, State DD Council, Medical School, ASPE
- **Design process:** Involve disability groups
- **Recruitment:**
 - Existing medical school practices, local facilities, community-based organizations for PWD
 - Avoiding the negative patient
- **Training:** Time for training and follow-up
- **Retention:** Attrition
- **Benefits for PWD:**
 - Pleasure and empowerment – training future health care providers
 - Stipend/payment adds value

Common Themes

- **Teaching students how to communicate appropriately and effectively**
- **Providing students with opportunities to interact with and become more comfortable with PWD**
- **Debunking common notions about PWD**
 - Inability to speak for themselves
 - Poor quality of life
 - Poor health inevitable



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Additional Accessibility Resources

- *Optimizing the Primary Care of Individuals with Intellectual and Other Developmental Disabilities: Everyone Is Important!* (DVD) Presented by Cleveland Clinic, Carl V. Tyler, MD
- Free Online Continuing Education on Disability resources for healthcare providers and office personnel: <http://nisonger.osu.edu/disabilityconted.htm>
- Disability Rights Education & Defense Fund: Healthcare Stories – videotaped interviews with people with diverse disabilities who speak candidly about their healthcare experiences <http://www.dredf.org/healthcare-stories/>
- Information about available tax credits to offset cost of improving accessibility: <http://www.cdihp.org/briefs/brief6-tax-incentives.html>
- Barrier Removal Tax Deduction: http://www.workworld.org/wwwwebhelp/barrier_removal_tax_deduction.htm
- Disabled Access Tax Credit (Section 44 of Americans with Disabilities Act): http://www.workworld.org/wwwwebhelp/disabled_access_tax_credit.htm
- US Dept of Justice Access to Medical Care for Individuals with Mobility Disabilities: http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm
- US Dept of Justice Standards for Accessibility of Equipment and Furniture for Individuals with Disabilities: http://www.ada.gov/anprm2010/factsht_equipment_anprm_2010.pdf



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You're Invited!

Next Health and Disability SIG meeting:

December 4, 2012, 12:00-1:15 pm

Join the SIG listserv!

Request to join on AUCD's website

OR

Email one of the SIG contacts to be added



Questions?

Please type any questions you may have in using the chat box feature.