Cultural Competence: Strengthening the Clinician's Role in Delivering Quality HIV Care to People with Disabilities

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Objectives

1. Discuss the implications of the Americans with Disabilities Act for providing clinical care.
2. Define 'disability in the context of HIV.'
3. Discuss attitudinal barriers against people with disability and compare/contrast to discrimination of persons with HIV.
4. Discuss strategies for providing culturally competent care to people with HIV and visual, hearing, mobility, speech-language, cognitive and/or emotional disabilities.

Definition of Disability

The *Convention on the Rights of Persons with Disabilities* states that:

"*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*"

HIV and Definitions of Disability under International and National Laws - UNAIDS

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Health Care Accessible for People with Disabilities: Medically Important, Legally Required

- **The Americans with Disabilities Act of 1990 (ADA)** is a federal civil rights law that prohibits discrimination against individuals with disabilities in every day activities, including medical services. The ADA requires access to medical care services and the facilities where the services are provided.
  - Private hospitals or medical offices are covered by Title III of the ADA as places of public accommodation.
  - Public hospitals and clinics and medical offices operated by state and local governments are covered by Title II of the ADA as programs of the public entities.
- **Section 504 of the Rehabilitation Act of 1973 (Section 504)** is a civil rights law that prohibits discrimination against individuals with disabilities on the basis of their disability in programs or activities, including health programs and services, that receive federal financial assistance, which can include Medicare and Medicaid reimbursements.
  - The standards adopted under the ADA to ensure equal access to individuals with disabilities are generally the same as those required under Section 504.

"Americans with Disabilities Act: Access To Medical Care For Individuals With Mobility Disabilities" July 2010
U.S. Department of Justice, Civil Rights Division, Disability Section and
U.S. Department of Health and Human Services, Office of Civil Rights
http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm

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Under the ADA and Section 504, Health Care Providers May Not:

- Refuse to allow a person with a disability to participate in, or benefit from, their services, programs or activities because the person has a disability.
- Apply eligibility criteria for participation in programs, activities and services that screen out or tend to screen out individuals with disabilities, unless they can establish that such criteria are necessary for the provision of services, programs or activities.
- Provide services or benefits to individuals with disabilities through programs that are separate or different, unless the separate programs are necessary to ensure that the benefits and services are equally effective.

"Your Rights Under The Americans With Disabilities Act" June 2006
U.S. Department of Health and Human Services, Office for Civil Rights
http://www.hhs.gov/ocr/civilrights/resources/factsheets/ada.pdf

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Under the ADA and Section 504, Health Care Providers Must:

- Provide services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.
- Make reasonable modifications in their policies, practices and procedures to avoid discrimination on the basis of disability, unless they can demonstrate that a modification would fundamentally alter the nature of their service, program or activity.
- Ensure that individuals with disabilities are not excluded from services, programs and activities because buildings are inaccessible.
- Provide auxiliary aids to individuals with disabilities, at no additional cost, where necessary to ensure effective communication with individuals with hearing, vision, or speech impairments. Auxiliary aids include such services or devices as:
  - qualified interpreters, assistive listening headsets, television captioning and decoders, telecommunications devices for the deaf [TDDs], videotext displays, readers, taped texts, brailled materials, and large print materials.

"Your Rights Under The Americans With Disabilities Act" June 2006
U.S. Department of Health and Human Services, Office for Civil Rights
http://www.hhs.gov/ocr/civilrights/resources/factsheets/ada.pdf

Is HIV a Disability?

Supreme Court Ruling: In June of 1998, the Supreme Court stated that people infected with HIV were entitled to protection under the Americans with Disabilities Act, regardless of their symptoms or lack of symptoms.

Pre-Existing Disability

Disability as a Consequence of HIV and other health Conditions

Episodic Disability

Approaching Disability from Multiple Lenses

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Minority Groupings

- People with disabilities comprise the largest minority numbering 52.6 million
  - 20% people with disabilities
  - 12.5% Latino
  - 12.3% African American
  - 4.3% Asian
  - > 1% HIV/AIDS

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Cultural Competence

The word culture is used because it implies the integrated pattern of human behavior that includes thought, communication, actions, customs, beliefs, values and institutions of a racial, ethnic, minority or social group.

The word competence is used because it implies having the capacity to function effectively.

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Disability as a Culture

Individuals with a disability are part of a distinct culture of shared experiences and health care needs.

What Makes Disability as a Culture Different from Other Cultures?

Disability is an "equal opportunity" and can happen to any of us at any point in our lives.

Most people
are not
born with a disability.

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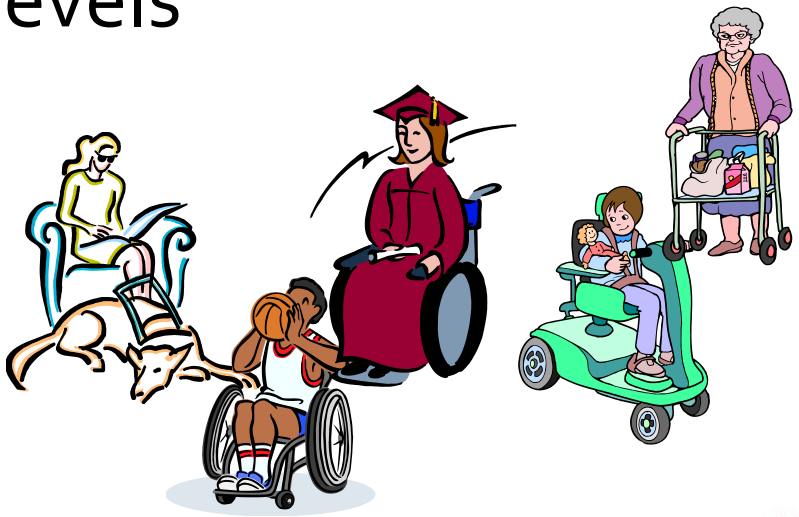
Diversity of Disability

Persons with disabilities represent ALL:

- Human characteristics
- Racial and ethnic backgrounds
- Social and economic levels
- Genders
- Ages
- Sexual orientations



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Culturally Competent Care

The delivery of health care services that acknowledges and understands cultural diversity in the clinical setting, respects health beliefs and practices, and values cross-cultural communication.

Culturally Competent Care

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.
(adapted from Cross et al., 1989)

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Culturally Competent Care

Cultural competence requires that health care facilities have the capacity to:

- Value diversity
- Conduct self-assessment
- Manage the dynamics of difference
- Acquire and institutionalize cultural knowledge of persons with disabilities and
- Adapt to diversity and the diverse cultural contexts of the persons with disabilities

Cultural Competency Assessment

Organizational level: policies – formal committees, community representation, clinical level and understanding bias, training curriculum, sensitivity awareness.
Personal level: personal values, mindful of differences, ability to reflect on actions, behaviors and bias.

Cultural Competence at the Facility Level

Culturally competent health care facilities are characterized by acceptance and respect for difference, continuing self-assessment regarding culture, careful attention to dynamics of difference, continuous expansion of cultural knowledge and resources, and a variety of adaptations to service models in order to better meet the needs of persons with disabilities.

Key Values for Cultural Competence

1. Inclusivity
2. Respect
3. Valuing differences
4. Equity
5. Commitment

RNAO, 2007

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Barriers to Primary Care Access

- Transportation challenges
- Inaccessibility of examination tables – massage tables
- Inaccessibility of communication systems
- Time constraints
- Cultural barriers
- Access to health insurance

Attitudinal Barriers Health Care Professionals

- People with disabilities rate their quality of life as average or better than average
- 86% of patients with tetraplegia rate their quality of life as average or better than average, but….
- ….only 17% of emergency-room doctors and other providers believe that this rating would apply to them if similarly disabled

Communication - General Guidelines

- Use person first language
- Consider the patient the expert about the disabling condition
- Identify yourself
- Address the individual
- Don't make assumptions
- Let the individual ask for assistance

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Implications for Providers

- Consider the patient the expert, especially if born with a disability or disabled in the not-recent past
- Use language that reflects positive views/ attitudes related to disability/impairments
- Avoid assumptions regarding quality of life, and be aware of one's own biases

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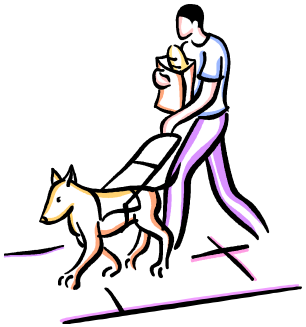
Implications for Providers-
Visual Impairment



- Identify yourself and others
- Use auditory mode, and don't use non-verbal/gestural communication
- Provide written materials in auditory format, computer disk, Braille, or large print, depending on preference

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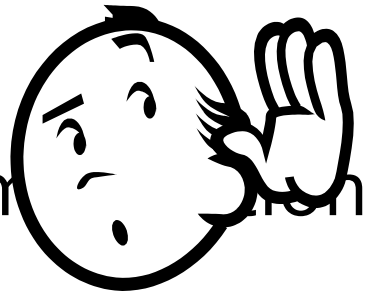
Implications for Providers-
Hearing Impairments

- Ask how you can facilitate communication
- Provide materials in written form
- Provide American Sign Language or other sign language interpreter
- Understand how to use a TTY (teletypewriter), or TDD (telecommunication device for the deaf)
- Hearing aids



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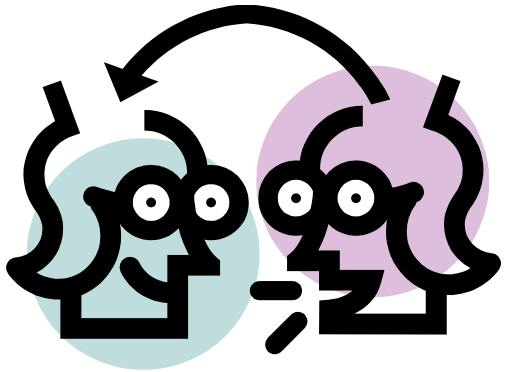
Implications for Providers-
Speech Impairments

- Allow time
- Don't pretend to understand
- Re-state what they have said
- Don't assume a cognitive deficit



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Implications for Providers-
Cognitive Disability

- Minimize distractions or over-stimulating environments
- Be aware cognitive impairments might affect the person's understanding of health condition or treatment recommendations
- Have patient re-state information to verify understanding

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Mental-Emotional Impairment and HIV

- Mental health issues
  - depression, substance use, bipolar disorder
  - 'positive living' with HIV
  - consider social interaction and sustaining motivation barriers to access and sustainability of care

Implications for Providers-
Physical Impairments

- Assure physical access
- Respect personal space, including wheel-chairs, assistive devices, assist dogs
- Do not propel wheelchair unless asked to do so

Roles for Rehabilitation

- Neurological
  - neuropathy, stroke
- Musculoskeletal
  - Weakness,
- Cardiorespiratory
  - Reduced activity tolerance, fatigue
  - Cardiac Rehabilitation
- HIV and Aging

Case Study-Willie

Willie is a 56 year old African America male, admitted to an inpatient rehabilitation facility (IRF) with a diagnosis of debility. He was admitted to the IRF from an acute care hospital.

The course of his recent illness is as follows:

Prior to the acute care admission the patient had been living alone, independently until he was admitted to an acute care hospital with endocarditis, secondary to strep viridians. After antibiotics course in the acute hospital the patient was discharged to a subacute facility for ongoing IV antibiotics. He went home from the subacute. He did not receive any rehabilitation services at home.

Subsequently, the patient came to the OP Infectious Disease Clinic with dysphagia and a cyst x 2 days between buttocks. He had visible oral thrush. Labs: CD 4= 0, FS glucose 440, VL (viral load) 491. He reported that he had fallen at home and that he was feeling weak. He was admitted to an acute care hospital for care. After his course of valcyclovir in acute care for perirectal herpes, Willie was discharged to an IRF for intensive (3 hours/day) therapy and intensive medical management (24 hour physician and nursing care). At admission to the IRF the patient had a BMI of 20.56. Albumin level was 2.2 g/dl.

His past medical history included HIV, HTN, GERD, Diabetes Mellitus, strep viridians, endocarditis, purgio nodularis, and chronic back pain.

Medications

- Rena-Vite multivitamin
- Nystatin solution 500,000 units, 5 milliliters orally 4x day
- Oxycodone immediate release 5 mg, 1 tab orally every 6 hrs for pain
- Pravachol 10 mg, 1 tab oral at night for cholesterol
- Raltegravir (Isentress) 400 mg 1 tab orally 2x day for HIV
- Ritonavir (Norvir) 100 mg, 1 capsule orally 2x day for HIV
- Triamcinolone topical, 0.1% cream to affected area 2x day PRN for skin rash
- Benadryl 25 mg 2 capsules, orally 2x day prn for itching
- Etravirine (Intelence) 100 mg 2 capsules 2x day for HIV
- Famotidine (pepcid) 20 mg 1 tablet orally for gastric distress
- Fluconazole, 100 mg 1 tablet daily for oral thrush
- Neurontin 300 mg 3 capsules, 3x day for neurogenic pain
- Insulin Glargine 20 units sub q with breakfast
- Insulin lispro 1-5 units subq with meals, sliding scale

Case Study Questions

- **What is your approach to this patient?**
- **What are your priorities for treatment?**
- **How will you assess for ability to participate in a rehabilitation program?**
- **What is the most appropriate rehabilitation setting for this person?**
- **What are your concerns during rehabilitation?**
- **What are your priorities for discharge planning?**

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Resources

- Disability and Health: Accessibility (Centers for Disease Control and Prevention)
  http://www.cdc.gov/ncbddd/disabilityandhealth/accessibility.html
- Removing Barriers to Health Care: A Guide for Health Professionals
  http://projects.fpg.unc.edu/~ncodh/rbar/
- Americans with Disabilities Act: Access To Medical Care For Individuals With Mobility Disabilities (U.S. Department of Justice; U.S. Department of Health and Human Services)
  http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm
- ADA Questions and Answers for Health Care Providers (National Association of the Deaf Law and Advocacy Center)
  http://www.wvdhhr.org/wvcdhh/directories/07toc/adaqahealthcarpro.pdf
- The ADA - Americans with Disabilities Act (National Alliance on Mental Illness)
  http://www.nami.org/Template.cfm?Section=Helpline1&template=/ContentManagement/ContentDisplay.cfm&ContentID=47065
- ADA Checklist: Health Care Facilities and Service Providers - Ensuring Access to Services and Facilities by Patients Who Are Blind, Deaf-Blind, or Visually Impaired
  http://www.afb.org/section.aspx?FolderID=3&SectionID=3&TopicID=32&DocumentID=529
- ADA Q & A: Health Care Providers (PACER Center – Champions for Children with Disabilities)
  http://www.pacer.org/publications/adaqa/health.asp

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