## Population Health Clerkship Living with a Disability

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#### What is a disability?

- The term disability is a legal term, not a medical term
- According to the ADA, a disability is defined as "a person who has a physical or mental impairment that substantially limits one or more major life activity."
- This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.





#### Top 10 Leading Disease/Disorder Categories Contributing to U.S. DALYs (2010)

<u>https://www.nimh.nih.gov/health/statistics/disability/us-leading-categories-of-diseases-disorders.shtml</u>

#### Demographics

#### FIG 1. Percentage of People in the US with Disabilities, 2008-2016



Rehabilitation Research and Training Center on Disability Statistics and Demographic







https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html

#### Demographics (from 2017 Disability Statistics Annual Report)

Poverty

• An earnings disparity of over \$10,000 in median earnings between those with and without disabilities continues a trend, which has existed since at least 2008 and has increased in magnitude since 2013.

Work

• The employment gap, difference between the employment percentage for people with disabilities (35.9%) and people without disabilities (76.6%), is 40.7 percentage points

# Trends (from 2017 Disability Statistics Annual Report)

Obesity

• At 12.6 percentage points, 2016 had the lowest obesity gap (the difference in the percentages of obesity for people with and without disabilities) since 2009. It was also the second straight year-to-year drop.

Drinking

• From 2009 through 2016, binge drinking percentage for people with disabilities varied from a low of 10.2% in 2010 to a high of 13.2% in 2009. This rate is lower than the rate among people without disabilities.

Smoking

• Over the past 8 years, the highest percentage of people with disabilities who smoke was 27.0% in 2009. This has been in annual decline since 2012 (from 26.0% to 23.4%). But in 2016, the percentage moved back up to 24.6%.

#### Medical Highlight: Pressure Sores

- Incidence: 0.4 percent to 38 percent in hospitals, from 2.2 percent to 23.9 percent in skilled nursing facilities, and from 0 percent to 17 percent for home health agencies.
- Treatment: offloading the offending pressure source, adequate drainage of any areas of infection, debridement of devitalized tissue, and regular wound care to support the healing process. If severe, surgery may be required. Avoid with pressure map.
- Other common medical problems include neurogenic bladder and congestive heart failure





#### **Interprofessional Care Teams**

- In general, patients with disabilities are served by virtually all professionals in the medical field, including physicians in all specialties.
  - For the purpose of this presentation, we will focus on care providers that cater to some of the unique needs of patients with disabilities
- Patients with disabilities that limit mobility are often seen in their homes by healthcare providers.



## Personal Care Attendants (PCAs) and Home Health Aides

- Trained caretakers that provide in-home help with dressing, bathing, using the restroom, cooking, etc.
- Qualifications: On-the-job training
- Home Health Aides are employed by agencies that dictate what they will do for the patient
- PCAs are employed by the patient directly so that the patient can oversee his/her own care on his/her own terms.
  - Available for free for patients on MassHealth Standard, CommonHealth, or a OneCare Plan
- PCAs and Home Health Aides are not directly involved in medical care but are often responsible for ensuring a patient takes his/her medicine, scheduling appointments, etc.
  - Patients may request that PCAs be present during appointments to ensure proper communication

#### **Occupational Therapists and Physical Therapists**

- Occupational Therapists (OTs): treat patients who are injured, ill, or disabled through the therapeutic use of daily activities to prepare the patient to be able to live and work
  - Qualifications: masters of doctorate degree in occupational therapy, state licensing
  - For patients needing wheelchairs, occupational therapists also work at wheelchair clinics, where they help patients find a properly fitting chair
- Physical Therapists (PTs): help patients who are injured, ill, or disabled to increase movement, maximize range of motion, and manage pain
  - Qualifications: doctorate degree in physical therapy, state licensing
- Communication with physicians is essential
  - Physicians refer patients to occupational therapists and physical therapists
  - Specific documentation is often required
- PTs and OTs work in rehabilitation hospitals, outpatient clinics, and in patients' homes.

#### Nurse Practitioners (NPs)

- Patients with disabilities age 21-64 qualify for Commonwealth Care Alliance (CCA) and Community Care Coordination (CCC) through MassHealth
  - These plans are largely NP-based
  - Patients are typically seen in their own homes by NPs once monthly and physicians once yearly
- NPs can assess patient needs, order testing, diagnose illnesses, formulate treatment plans, and prescribe medications.
- In Massachusetts, NPs can diagnose and treat patients independently but may only prescribe medications with physician supervision
- Qualifications: Masters in Science of Nursing (MSN) or Doctorate of Nursing Practice (DNP)
- NPs work in hospitals, outpatient clinics, in patients' homes, etc.

#### Physicians

- People with disabilities see physicians in all specialties
- Some physician visits will be related to the patient's disability, but others will not
- Ask patients about their disabilities when necessary, but understand that some visits are not disability related
- Patients know their disability best
  - Ask questions and listen carefully to answers
  - Patients are often more educated than physicians on the intricacies of living with their disabilities



#### Interacting with the Team

- Communication and respect are key
  - All team members have unique knowledge of the patient's needs
- Documentation is important
  - OTs and PTs base treatment plans off of physician documentation of the illness, injury, or disability
  - Physician documentation of a patient's disability can also qualify and disqualify him/her from many state resources and programs
  - For many insurance companies, including Medicare, the way a physician documents the diagnosis can determine the quality of wheelchair the patient is eligible to receive



## Massachusetts Commission for the Deaf and Hard of Hearing



- Advocate for accessibility in medical practices and hospitals, schools, workplace, etc.
- Providing interpreters for various needs
  - Challenge of small Deaf community & interpretation with privacy
- Video remote interpreters, CART/stenographers
  - Challenge of connectivity, 2D vs 3D signing, deaf-blind patients
- Success should be a standard- patients able to access various parts of life like any other
- Failure equals communication breakdown and disservice

## Center for Living and Working



- Advocate for education, housing, employment, and recreation accommodations
  - ADA consultation
- Individualized Education Plans (IEPs) in schools, Pre-Employment Transition Services/TAP
- Consumer-driven independent living
  - PCAs
  - Skills training
- Difficulty finding affordable accessible housing, esp. In Worcester



#### **Massachusetts Rehabilitation Commission**

- Disability Determination Services
  - SSI and SSDI benefit determination
- Home Modification Loan Program
- Assistive Technology Services
  - Easter Seals, Wheelchair clinics
- Vocational Rehabilitation
  - In conjunction with CLW and other organizations



**Massachusetts Rehabilitation Commission** 



#### What can healthcare professionals do?

- Be aware of resources available for individuals that are deaf, blind, physically, intellectually or developmentally disabled
  - Gov't agencies, financial aid programs, technology/modifications, job assistance
- Push for greater accessibility in your practice
  - If you do not see accessible scales, accommodations for deaf/hard of hearing, etc. ask supervisors how they could be obtained
  - If you ever EVER see patients being examined in their wheelchairs, intervene and ask when the last time they were weighed and examined outside of one
- Treat all patients equally & focus on the person, not the disability



#### Service and Experiential Learning



- Day 1: Introductions and icebreakers with the students at **Worcester Public** Schools Transition Program and New Citizens Program
- Day 2: Rotation stations focusing on solo doctor's office visits for students in the Transition Program and New Citizens Program
  - Key goals were for the students to learn about self health advocacy and work on communication skills
  - Key goals for us: Work on effective explanation and communication methods and reduce "white coat anxiety"



#### Ask a Doctor

## Nutrition

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HOLY CROSS



#### Medical Forms



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**Mass Department of Developmental Services** 

Worcester Assistive Technology Center







**Spaulding Rehabilitation Hospital** 

REHABILITATION NETWORK

**Easter Seals Boston** 

**Commonwealth Community Care** 







**Disabled Persons Protection Commission (DPPC)** 

Mass Commission for the Deaf and Hard of Hearing

- Steven A. Florio
  - Commissioner
- **Mass Rehabilitation Commission**
- Ashley Stone
  - Transition Services Commission





#### **Center for Living and Working**



- Meg Coffin, CEO
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- Jennifer Miller, Personal Care Management Program Manager
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- Lisa lezzoni, MD, MSc
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**Massachusetts Rehabilitation Commission** 



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## Thank you!

