

Health & Healthcare Advocacy for People with Disabilities

Shane Janick, MPH
Executive Director



Valerie Chadwick, BSN, RN
Health Advocacy Director

Our Mission

The Arc of Philadelphia's mission is to advocate with and for all children and adults with intellectual and developmental disabilities (IDD) and their families, to promote active citizenship, self-determination, and full inclusion.



Agenda

- The Arc of Philadelphia's HealthMeet
- Historical context
- Home Community Based Services (HCBS)
- Population level health and background
- Models of disability
- Stigma and bias
- Inclusive practices
- Diversity of Disability



Learning Objectives

- Understand the need for Health Advocacy for the population with IDD
- Explain the historical context of Disability and Medicine
- Recognize the importance of Home/Community-Based Disability Services
- Identify health disparities and inequities among the population with IDD
- Apply the Social Determinants of Health to communities with disabilities
- Develop strategies to provide “inclusive healthcare” for people with IDD

Our Partners

University partners:

- Medical
- Dentistry
- Rehabilitation Sciences
- Undergraduate and Graduate Nursing
- Public Health

Home/Community-Based Services partners:

- SpArc Services




Did you know?

16% of all Philadelphians—roughly **246,000** people—had a physical, emotional, or cognitive disability in 2016, according to the latest data from the U.S. Census Bureau.

Nationally, **1 in 4** people in the US have a disability.

How many of you have personal connections or professional experiences with people with disabilities?

Historical Context

- Institutionalization
- Medicine's relationship to disability
 - Referrals for state-institutions at birth
 - Quality-of-life metrics
 - Patient autonomy
- Disability Rights Movement
 - Institutionalization  Home/Community Based Services (HCBS)



Home/Community-Based Services (HCBS)

- Residential providers
 - “Group homes”
- Adult-Day Programs
 - Therapeutic activities
- Home and Community Habilitation
 - Skilled-Nursing staff
 - Individual support from staffing agencies
- Supported Employment
 - Vocational Rehabilitation/Job Skills/Job Readiness

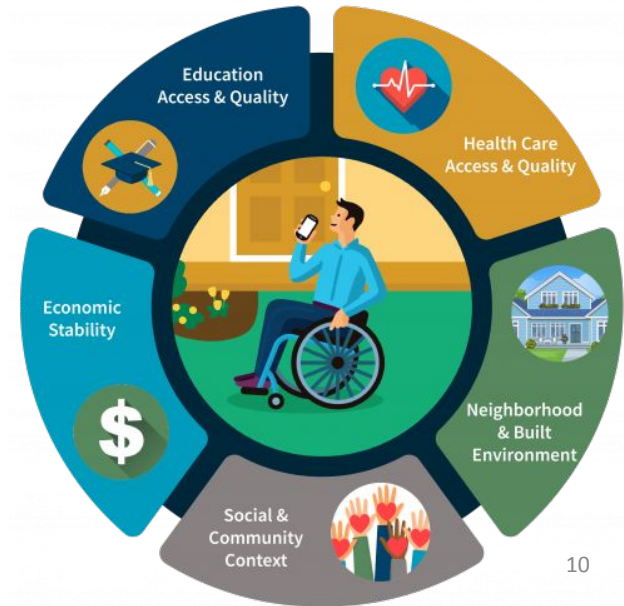


Social Determinants of Health (SDOH)

“The conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”

-The World Health Org.

- Adult HCBS
 - Residential providers
 - Adult-Day Programs
 - Home and Community Habilitation
 - Supported Employment
- Child Services
 - Early Intervention
 - Special Education



What do you think they want?!

to make my own decisions

information I can access

to be treated with respect

to be asked



Statement of Need and Background

Disability \neq Poor health

- Comorbidities
- Health inequities
 - Lower life expectancy
 - Obesity rates
 - Podiatric health
 - Oral health
- Attributed to and exacerbated by...
 - Lack of required education
 - Health insurance barriers
 - Socio-economic status
 - Physical/environmental barriers
 - Social and attitudinal barriers
 - Disability bias



Statement of Need and Background

Patients with IDD are more likely to report being in poor health and have higher rates of:

Undiagnosed hearing and vision impairments	Obesity	Poor dental health	Diabetes, arthritis, and cardiovascular disease including asthma	Have shorter average life expectancy than the general population
Less likely to receive preventive screenings and vaccinations	Most common causes of death differ from the general population and show higher rates of mortality due to illnesses/conditions less likely to lead to death in general population		Most likely to have poorly managed chronic health conditions	Higher rates of prescribed psychotropic medications

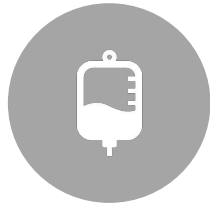
Social determinants of Health contribute to a "cascade effect"

“The Fatal Five”

PREVENTABLE HEALTH DISPARITIES COMMONLY EXPERIENCED AMONG PEOPLE WITH IDD



ASPIRATION



DEHYDRATION



CONSTIPATION

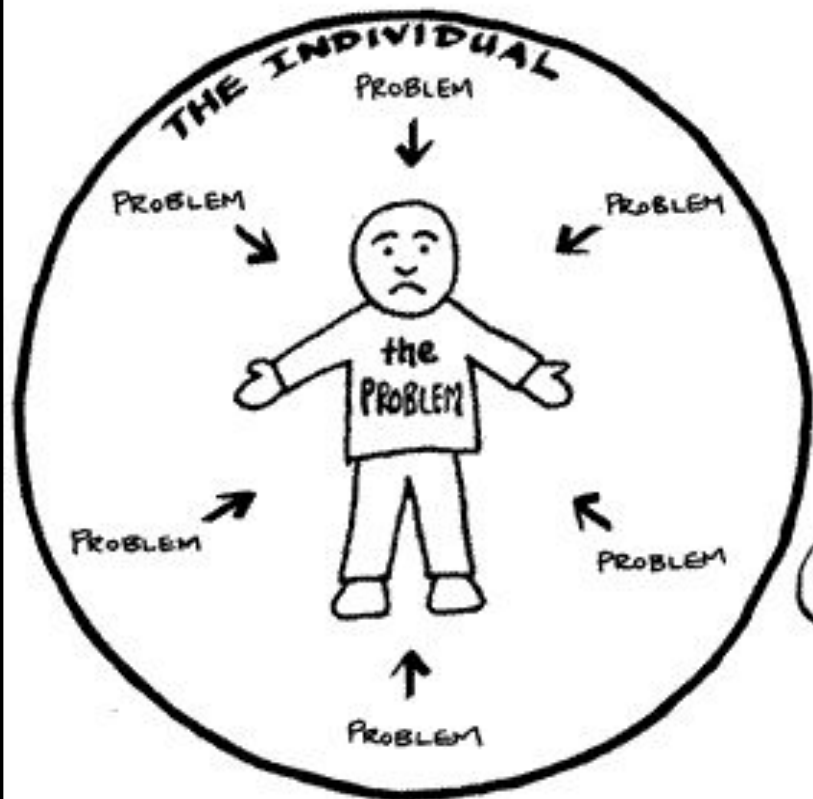


SEIZURE

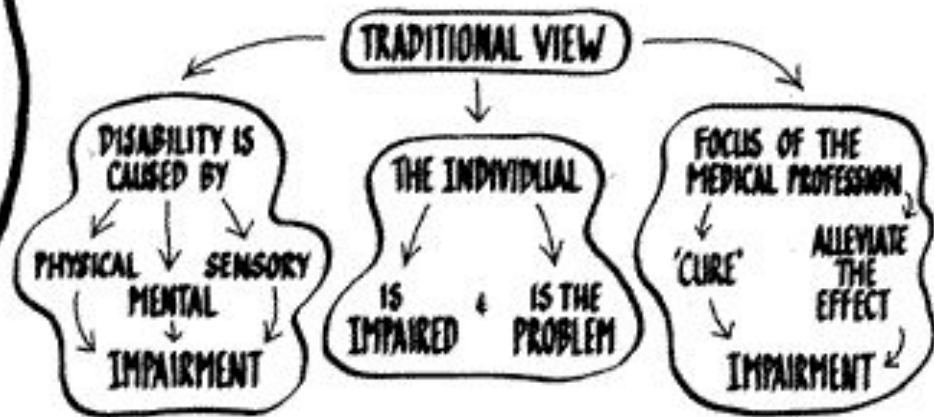


SEPSIS/
INFECTION

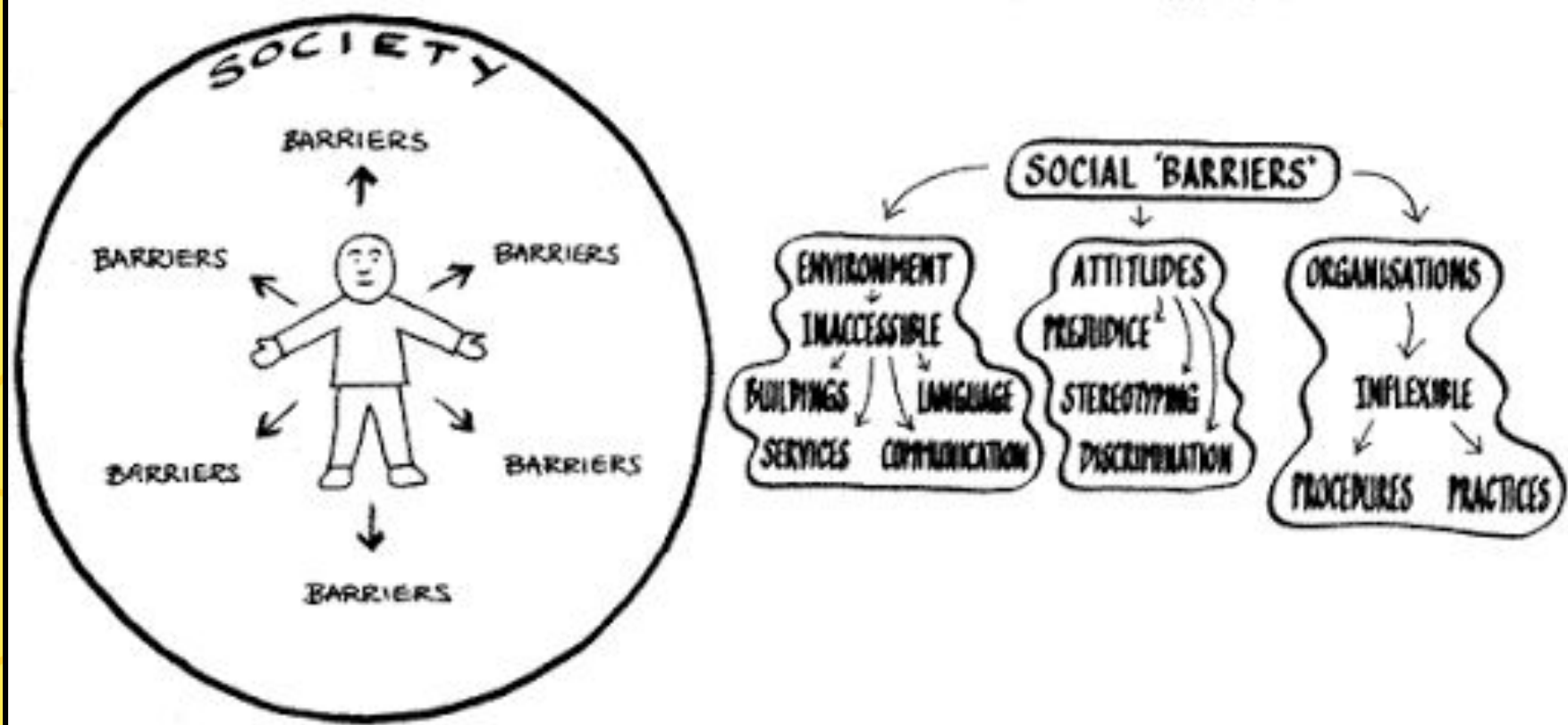
THE MEDICAL MODEL OF DISABILITY



IMPAIRMENTS AND CHRONIC ILLNESS
OFTEN POSE REAL DIFFICULTIES BUT
- THEY ARE NOT THE MAIN PROBLEMS



THE SOCIAL MODEL OF DISABILITY



Her **impairment**
is the problem!
They should
cure her or give
her prosthetics.

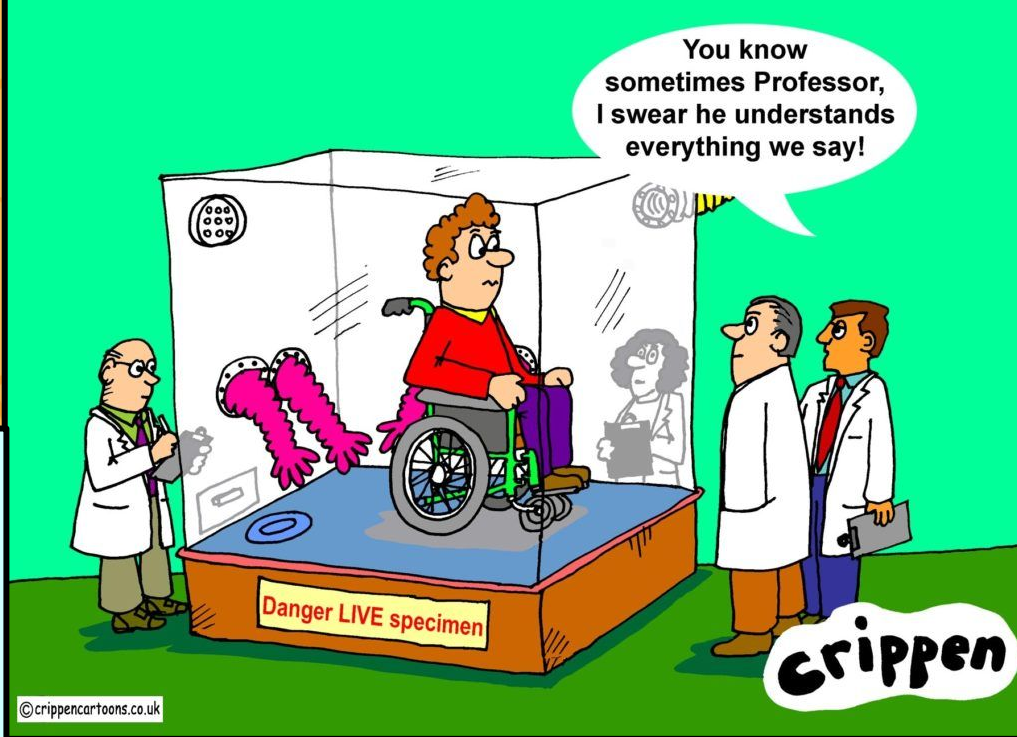
The *medical model*
of disability



The **stairs** are
the problem!
They should
build a ramp.

The *social model*
of disability

Achieving inclusive practices by...



...reducing

- Biases
- Stereotypes
- Stigma

***Crip Camp* video clips**

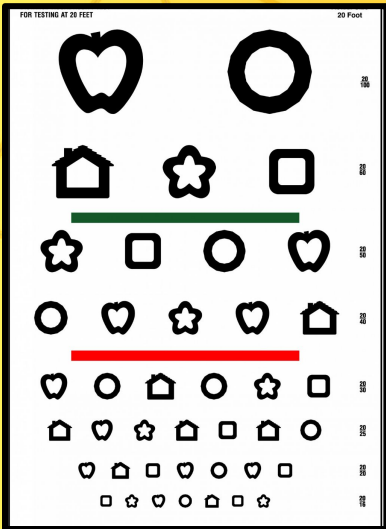
Biases & Stigmas in Healthcare

- **82.4%** of physicians reported that people with significant disability have worse quality of life
- **40.7%** of physicians were very confident about their ability to provide the same quality of care to patients with disability
- **56.5%** strongly agreed that they welcomed patients with disability into their practices
- **18.1%** strongly agreed that the health care system often treats these patients unfairly

Inclusive Practices

- Person centered care
 - Creative, Flexible, Accommodating
- “Presuming Competence”
 - Tone of voice/Body language
 - Follow a caregiver’s lead if requested
- Office-space readiness
 - Physical and social accommodations
 - Staff training
 - Tools and equipment
- Communication
 - Person-first language
 - Practice active listening
 - **Ask** questions that will help you understand the patient
 - 1 in 4 people with IDD utilize “non-traditional” modes of communication

More practices!



Diversity of Disability & Identity



The Arc.

of Philadelphia

part of the SpArc Philadelphia
family of organizations

- Physical disability
 - Mobility differences
 - Bodily differences
- Intellectual Disability (ID)
 - Spectrum: Severe to Moderate
 - “Dual diagnosis:” ID and Psychiatric diagnosis
- Sensory disability
 - Deaf/Hard of hearing
 - Blind/Low vision
 - Sensory Processing Disorder



- Autism
 - Autism Spectrum Disorder
 - Autism Awareness Movement & IDD
 - 1 in 3 people with Autism have ID

Conclusion

- Addressing current gaps to inclusive practices
 - Awareness and education
 - Some solutions
- Vision / Long-Term Goals
 - Decreased biases and stigma of of people with IDD in healthcare settings
 - Improved quality of healthcare for people with IDD



Questions?

Shane Janick, MPH
Executive Director

SJanick@ArcPhiladelphia.org

Valerie Chadwick, BSN, RN
Healthcare Advocacy Director

VChadwick@ArcPhiladelphia.org

*Thank
you!*

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Health Screenings

- Energy and enthusiasm
- Focus on social and communication skills
- No expectation to complete each screening
- Quick survey
- Picture!

