Change How You See, See How You Change, Positive Exposure
The Spirit of Difference

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Learning Objectives

• Discuss ableism/bias and potential health implications of how people with disabilities are viewed in their communities.

• Introduce Positive Exposure, which utilizes photography and video to transform perceptions of people living with genetic, physical, and behavioral differences.

• Discuss FRAME, a web-based educational library of genetic conditions that is changing the way healthcare students see people living with genetic differences.
Over 14 million children in the U.S. have a disability.
People with disabilities experience healthcare disparities:

- Screening and preventive services
- Access to care
- Health status and health outcomes
- Cancer diagnosis and treatment
- Satisfaction with care
People with disabilities experience health disparities:

- Obesity
- Diabetes
- Cardiovascular disease
- Asthma
- Arthritis
- Mental health conditions: depression, anxiety
Context: contributors to disparities

- **Patient-level factors:**
  - complex underlying health conditions and competing priorities
  - disadvantages in social determinants of health

- **Systems-level factors:**
  - inadequate training of healthcare professionals
  - ineffective communication accommodations
  - physical access barriers
  - inadequate knowledge among physicians about legal requirements to provide equitable care under the Americans with Disabilities Act (ADA) of 1990
  - Erroneous assumptions about people with disability
  - Ableism attitudes among clinicians
  - ? Physician bias
Ableism is the discrimination and oppression of disabled people; the societal belief that being able-bodied is “normal” and is preferred.

A result of bias against people with disabilities.
microaggressions/macroaggressions

internalization of ableism/oppression

mental health concerns: anxiety, depression, isolation, feelings of inferiority, powerlessness, negative body image

Internalization of ableism

• ...if you are born disabled, your parents need education on everything their child can do. Instead the doctor comes and says, “This is what is wrong, and this ... and this... and this.” When rather someone should come and say, “These are the resources available for you .... Your child can do this ... and this ... and this.” The focus is too often on what is wrong with the baby but not what the baby is capable of.

• There are often too little expectations towards disabled children. You know, many parents really have to fight in order to have the same expectations aimed at their disabled child as any other child.
Internalization of ableism

Ása: There is a connection between depression and anxiety and for example, disability. And you know, it is most likely because society has a negative view of disability.

Sólrún: I think that society could be more positive. “Yes, okay, you are like this!”

Researcher: Can I ask you, Ása, when you say the connection between depression, anxiety and disability is because of society, can you name an example?

Ása: It’s because of prejudice towards disability. People with disabilities do not think they are acceptable to others, and then they isolate themselves and become anxious.

Sólrún: I became depressed because of my disability, but also because of prejudice from others.
Bias

• Preconceived attitude or belief, conscious or unconscious, regarding a group of people that influences how we perceive, interact, and behave toward the group.

• Studies of racial/ethnic bias among physicians have found that unconscious and conscious beliefs significantly effect treatment decisions, patient outcomes, and other aspects of care.

• If parallel effects hold true for people with disability, physician bias toward disability likely contributes to known healthcare disparities in this population.
Physicians’ Perceptions Of People With Disability And Their Health Care

**ABSTRACT** More than sixty-one million Americans have disabilities, and increasing evidence documents that they experience health care disparities. Although many factors likely contribute to these disparities, one little-studied but potential cause involves physicians’ perceptions of people with disability. In our survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5 percent strongly agreed that they welcomed patients with disability into their practices, and 18.1 percent strongly agreed that the health care system often treats these patients unfairly. More than thirty years after the Americans with Disabilities Act of 1990 was enacted, these findings about physicians’ perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could contribute to persistent health care disparities affecting people with disability.
Perceptions of Disability - Physicians

• 82% of physicians report that people with significant disability have overall worse quality of life than other people
• 41% of physicians are very confident in their ability to provide equal quality care to people with disability
• 56% strongly welcome people with disability into their practices
  • Women physicians more welcoming
  • Younger more welcoming
  • Physicians confident about their ability to provide care to disabled people more welcoming
  • University setting more welcoming than private practice

Perceptions of Disability - Patients


- 58% of blind, very low vision
- 73% of deaf, very hard of hearing
- 32% of walker users
- 20% of manual wheelchair users
- 16% of power wheelchair users

https://www.cdc.gov/nchs/nhis/nhis_disability.htm
The Disability Paradox

• Many people with serious and persistent disabilities report that they experience a good or excellent quality of life, even when to most external observers these people seem to live a less desirable daily existence.

• **Quality of life:** an individual’s perception of their well-being and general satisfaction with life (personal perspective)

• Subjective life satisfaction of disabled people is usually comparable to that of non-disabled people.
  • People with different expectations will report that they have a different quality of life even when they have the same clinical condition

• Many people with disabilities, particularly if their conditions are congenital or long-term, do not necessarily perceive their disability as a problem or pathology.

Given potential bias of physicians, how do we ensure that people with disability get equal quality care?

Raises questions about care for people with disability in times of scarce resources (COVID-19 pandemic).

- Crisis Standards of Care (CSC)
- **3/31/2020 Office for Civil Rights at the U.S. Department of Health and Human Services**, “in this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.”
- States changed CSC
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Why should people with disability need to prove to their doctor that they value the quality of their life to get equal quality of care?
Causes and ways to help

- Ableist attitudes dominate medicine – training focus on medical model (pathology)
  - Functional model (environmental context)
- In our culture we are implicitly bound to think of able-bodied people when we think of a good quality of life
  - Biases come from our culture, but what we teach ourselves, what we choose to associate, is up to us
- Lack of exposure of learners to disabled people, in medical school and often throughout life
  - All levels of medical training should include more training about disability
  - Make medical school education more accessible to disabled people
  - Use disability self-advocates in medical training
  - **Change training to provide greater empathy and understanding about patients’ daily lives**
  - Rick Guidotti, Positive Exposure
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POSITIVE EXPOSURE
1. Du satín effet nylon pour duo de saison

À gauche. Manteau façon chausson en satin mat et sisal, coupe origine (Rayna
Tayema/Atlantic), robe de saloon (Ralph Lauren), bottes hauts (Carven). À droite. Manteau de
satin fourrure à motifs léopard, épaules décrochées et coupe prête
du corps (Dior); robe sans manches, en tissu de soie noire (Dior).
et se porte surtout sur pantalon cigarette...

Dessous, tout au plus, un licou ou un bandeau.
ALBINISM
CHANGE
HOW YOU
SEE, SEE
HOW YOU
CHANGE
POSITIVE
EXPOSURE
REDEFINING BEAUTY

Chanda McMillan, 48, is the president of NOAH (National Organization for Albinism and Hypopigmentation), a support group for people with albinism. Most of our subjects—none of whom are professional models—are NOAH members.

Eyewitness: Photographer Rick Guidotti opens our eyes to the beauty of albinism.
Turner syndrome (XO Female)

*Generally characterized by a slight mental handicap, fairly distinctive stature, obesity, and a webbed neck.

Abnormalities of Autosomal Chromosomes

- Edwards syndrome (trisomy 18, 47,XXX+18)
  - Most frequently results from nondisjunction resulting in missed 18
  - Marked by mental retardation, prominent occiput, occipital encephalochelys, agenesis of the corpus callosum, congenital heart disease, and very short life span

- Patau syndrome (trisomy 13, 47,XXX+13)
  - Manifested by mental retardation, macrocephaly, feeding difficulties, poor suck, congenital heart disease, and short life span
MARFAN Syndrome
Billy
Caleb living with Achondroplasia
Dr. Nadia
Maggie and Danielle at the Costello Syndrome Conference
Jahzara living with Goldenhar syndrome
Jayda living with 22q11.2 deletion
Lukas living with Fragile X syndrome
Simone living with Down syndrome
Ronan living with Prader-Willi syndrome
Curtis and Alex living with Vitiligo
Jasper living with Angelman syndrome
SPINAL MUSCULAR ATROPHY Family Conference
Khloee
The Amazing Judith Heumann
Gaten living with Cleidocranial Dysplasia
THE UNDIAGNOSED

RICK GUIDOTTI POSITIVE EXPOSURE
WILHELM FOUNDATION
함께하는 소중한 추억

희귀질환 포토 프로젝트
Kaelin living with Sturge-Weber syndrome
Self - Acceptance = Self - Esteem = Self - Advocacy
PEARLS Project

Featured Ambassadors

Grace
Rebecca
Talia
PJ living with Arthrogryposis Multiplex Congenita
FRAME
FACES REDEFINING THE ART OF MEDICAL EDUCATION
REPRESENTATION OF PATIENTS

EPISODE 1: DERMATOLOGY
REPRESENTATION OF PATIENTS

EPISODE 2: AGING
Amir

Textbook BEAUTY
ANGELMAN'S SYNDROME
Kaelin

TEXTBOOK BEAUTY: STURGE WEBER SYNDROME

POSITIVE EXPOSURE
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The spirit of difference

CHANGE HOW YOU SEE,
SEE HOW YOU CHANGE.
Q & A

THANK YOU!
Thank you for joining us!

We hope to see you all next year...