

# Self-Advocacy and Healthcare



**#1** On a personal level, doctors need to know all about your life. They need to know your strengths to give you good advice about being healthy.



**#2** As a group, self-advocates are learning about health disparities. We are speaking up so people with disabilities get the healthcare they need.

# This Presentation Was Organized by:



**Lisa Iezzoni,  
Harvard Medical  
School**



**Max Barrows,  
SARTAC**



**Katherine  
Cargill-Willis,  
Administration  
on Disabilities**

# What is Quality Of Life?

---

Marcie is very happy and satisfied about her life.



Jessica is NOT very happy and satisfied about her life.



# Doctors were asked

---

Do you believe the overall quality of life of people with disabilities is better, the same or worse than nondisabled people?

- 17% said the same or better than nondisabled people
- 44% said a little worse than nondisabled people
- 39% said a lot worse than nondisabled people

# Doctors Need To Know All About Your Life

---



Don't assume  
what I can &  
cannot do!

- Doctors help us make decisions about what to do when we get sick.
- They need to really know us to be able to give good advice.

# Doctors Need To Know All About Your Life

---

Most of the time  
we talk to our  
doctors about  
being sick



# Doctors Need To Know All About Your Life

---



## First Visit and Annual Exam

**Share Your 1-Page Profile which includes:**

- What are you good at doing?
- What are you proud of?
- What do people thank you for?
- What do others admire about you?

**Tell them great things about you.**



# Now We Will Talk About Health Disparities



This report gives information about the problems people with disabilities face being healthy. Our slides include information from studies described in Healthy People 2020.

<https://www.healthypeople.gov/2020>



# Disabled People Have Problems Getting:

---

- Screening for health problems
- Services to keep a person healthy
- Reproductive healthcare
- Pregnancy healthcare
- Finding out if we have Cancer
- Getting cancer treatment



# What Self-Advocates are Saying About Health Disparities

- Health care providers need more training to care for adults with disabilities
- Many adults with disabilities still go to a pediatrician because of a lack of doctors who treat adults with disabilities
- We struggle to use health and wellness programs because they are too difficult to understand
- It is difficult to get private insurance or Medicaid to pay for specialized equipment and long-term therapies



# What Self-Advocates are Saying About Health Disparities

- Providers often **make incorrect assumptions** about our lives, our abilities, our experiences, our dreams. They often do not give us the information and/or treatment we need.
- People with disabilities are more committed to staying healthy when we are in charge of decisions about our health.
- *“When we show our emotions or tell people how we feel we often get more meds.”* There is a lack of therapists with experience working with people with disabilities

# Studies About Health Disparities Say...

---

- People with disabilities often have complicated health problems.
- Many people with disabilities are poor and struggle getting housing and transportation.
- Lack of training of health care professionals.
- Might not get accommodations to communicate.
- Medical equipment is not accessible, including weight scales and exam tables.
- Doctors and hospitals do not follow the ADA.

# In a Study with 714 Doctors...

---

When asked to compare how they treat patients with disabilities with how they treat patients without disabilities...

- 42% were confident they provide same quality of care
- 48% were somewhat confident they provide same care
- 10% were not very confident or not at all confident

# An example of a health disparity or unequal treatment

## Quality Of Care of People with Physical Disabilities

How would you rate the quality of care of patients with **physical disabilities**?

- 44% said the same or better than with nondisabled people
- 46% said A little worse than with nondisabled people
- 9% said A lot worse than with nondisabled people

# An example of a health disparity or unequal treatment

## Quality Of Care of People with Mental Health Issues

How would you rate the quality of care of patients with **mental health issues**?

- 23% said the same or better than with nondisabled people
- 41% A little worse than with nondisabled people
- 36% said A lot worse than with nondisabled people



# An example of a health disparity or unequal treatment

---

## Doctors Need to Know How Much You Weigh

- People who are overweight might get sick more often. They might get heart disease and other illnesses.
- Doctors need to know your weight to know how much medicine to give you.

**One study said only 22% of doctors use an accessible scale for patients with physical disabilities.**

## An example of a health disparity or unequal treatment

---

### Can You Get On the Exam Table at Your Doctor's Office?

- One study said only 40% of doctors use an exam table that works for people with physical disabilities.
- Sometimes a person is examined while sitting in their wheelchair. Self-Advocates want to get a complete exam just like people without disabilities.

# Doctors were asked

---

How much do you know about your legal responsibilities to follow the ADA when caring for patients with disability?

- A lot = 14%
- Some = 50%
- A little = 28%
- Nothing = 8%

