

# CDC PUBLIC HEALTH GRAND ROUNDS

## Addressing Gaps in Health Care for Individuals with Intellectual Disabilities



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U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

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Introduction to session on addressing gaps in health care for individuals with intellectual disabilities.

# Improving Health for People with Intellectual Disabilities



## **Georgina Peacock, MD, MPH, FAAP**

*Director, Division of Human Development and Disability*  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

- Dr. Georgina Peacock introduced herself as the director of the division of human development and disability. This division is part of the Centers for Disease Control and Prevention.
- Dr. Peacock leads programs to improve health for people with and at risk for disabilities. She is also a pediatrician and helps families make health decisions to have better health and quality of life.
- Today's presentation is about improving the health of people with intellectual and developmental disabilities.

# Intellectual and Developmental Disabilities

## ➤ Developmental Disability

- Group of conditions due to an impairment of physical, learning, language, or behavior areas
- Originates before 22 years of age
- Examples include cerebral palsy, autism spectrum disorder, and intellectual disability

## ➤ Intellectual Disability

- Characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills
- Originates before 18 years of age
- IQ of 70 or lower
- Often included as one of several developmental disabilities

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) See pp. 1683-84  
[acl.gov/sites/default/files/about-acl/2016-12/dd\\_act\\_2000.pdf](http://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf)

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- People with developmental disabilities might find it difficult to do things like walking or running, learning, speaking, or controlling their behavior.
- Developmental disabilities happen before a person is 22 years old.
- Some examples of developmental disabilities are cerebral palsy, autism spectrum disorder, and intellectual disability.
- People with intellectual disabilities can have challenges doing everyday social and practical things like shopping and bathing.
- Intellectual disabilities happen before a person is 18 years old.
- People with intellectual disabilities have an IQ of 70 or lower.

## Identifying People with ID/DD in the United States

- **About 7.4 million people in the U.S. live with intellectual and developmental disabilities (ID/DD)**
- **Estimates of people with ID/DD vary**
  - Definitions or diagnoses of similar conditions sometimes overlap
  - Different levels of data collection can overestimate or underestimate
    - National, state, local, tribal, and organizational data
  - Lack of national longitudinal data







Larson SA, Eschenbacher HJ, Anderson LL, et al. Research and Training Center on Community Living, University of Minnesota (2018). Available at: [rsp.umn.edu/archive](http://rsp.umn.edu/archive)

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- About 7.4 million people in the U.S. have intellectual and developmental disabilities.
- Some disabilities are defined in slightly different ways. So when different sources of information are combined, too many or too few people with intellectual and developmental disabilities might be counted.
- There is little information about how their healthcare needs change over their lives.

## Characterizing the Health Needs of People with ID/DD Using Available Data

### Risk Factors of People with Cognitive Disabilities Versus Without Cognitive Disability, 2017, BRFSS

	With Cognitive Disability	Without Disability
 Have Obesity	38%	26%
 Smoke	32%	13%
 Have high blood pressure	41%	26%
 Be inactive	43%	24%



CDC created DHDS to provide quick and easy access to data on demographics and health information about adults with disabilities.

[www.dhds.cdc.gov](http://www.dhds.cdc.gov)

CDC, NCBDDD, DHDD. Disability and Health Data System (DHDS) Data [online]. Accessed September 9, 2019  
2017 Behavioral Risk Factor Surveillance System (BRFSS) data

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- One way we describe health findings is by looking at national surveys such as the CDC Behavioral Risk Factor Surveillance System or BRFSS.
- This survey identifies people with cognitive disabilities. People with intellectual disabilities are likely to be included in this group of people with cognitive disabilities, but the group may also include people with memory loss. This is an example of making the best use of information that we have.
- In this data, people with a cognitive disability are more likely to have obesity, smoke, have high blood pressure, and be inactive than people without a cognitive disability.
- The Disability and Health Data System, also called DHDS, is a quick and easy way to get information on health for adults with disabilities.
- This information can be used to develop programs to help people with disabilities have better health. This information is available at the state and national level.

## Health Outcomes and Costs for People with Intellectual and Developmental Disability (ID/DD)

### ➤ Identified disparities in health outcomes

- More likely to experience poor health outcomes, unmet healthcare needs, victimization, and early mortality

### ➤ Identified disparities in costs

- During 2001–2011, in one state, Medicaid members with ID/DD experienced over 21,000 potentially avoidable visits to the emergency department with costs over \$35 million



Mahoney A, Poling A. *J Dev Phys Disabil.* 2011;23(4):369-376

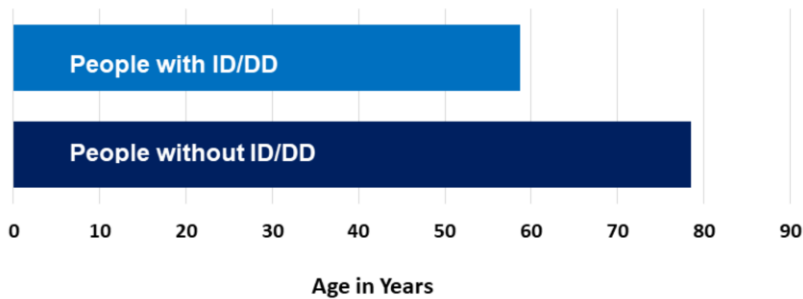
McDermott S, Royer J, Mann JR, Armour BS. *J Intellect Disabil Res.* 2018 Mar;62(3):165-178

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- Research suggests that people with ID/DD are more likely to experience poor health, have unmet healthcare needs, be a victim (such as sexual abuse) and not live as long as people without intellectual and developmental disabilities.
- Analyses of South Carolina's Medicaid data showed that from 2001-2011,
- Medicaid members with ID/DD had more than 21,000 potentially avoidable visits to the Emergency Department
- That means being seen in Emergency Dept for something that could have been treated in an outpatient visit
- Generating costs of over 35 million dollars

## People with Intellectual and Developmental Disability (ID/DD) Have Shorter Life Expectancy

Average Life Expectancy for People with ID/DD in Selected State Service Systems, 2009–2011, Compared to U.S. Population, 2009



On average, people with ID/DD die about 20 years younger than the general U.S. population

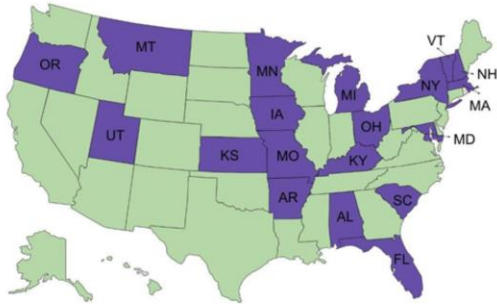
Lauer E, McCallion P. *J Appl Res Intellect Disabil.* 2015 Sep; 28(5):394-405

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- A study showed that people with intellectual and developmental disabilities do not live as long as people without intellectual and developmental disabilities.
- But, people with intellectual and developmental disabilities are living longer than they have any time in past.
- It is important to find ways to improve health and health care for people with intellectual and developmental disabilities.

# Using Data to Address Health Care Needs of People with ID/DD

## 19 Funded State Disability and Health Programs



[www.cdc.gov/disabilities](http://www.cdc.gov/disabilities)

## ➤ CDC works with

- 19 state disability and health programs to adapt evidence based interventions

## ➤ National organizations

- American Public Health Association
- Association for University Centers on Disability
- National Association of Chronic Disease Directors
- National Association of County and City Health Officials
- National Center on Health Physical Activity and Disability
- Special Olympics
- Many more partners!

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- CDC works with 19 state disability and health programs.
- We also work with many national partners including those seen on this slide.
- The other speakers on the panel will also talk about their work for people with intellectual and developmental disabilities.



## CDC Future Directions: Improve Estimate of People with Intellectual and Developmental Disabilities (ID/DD)

- **More accurately estimate the number of people with ID/DD in the U.S. population and their health needs**



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- CDC will continue to work with state, national, and federal partners to find ways to better identify how many people are living with intellectual and developmental disabilities.
- Two reports have recently come out.
- One looks at identifying persons with intellectual and developmental disabilities in national surveys.
- The second looks at what information is available at the state level and local level about people with intellectual and developmental disabilities.

## CDC Future Directions: Use Available Data Sources

### ➤ Use data to prioritize research that can be translated into action to improve the health of people with ID/DD

- Implementing interventions
- Informing policies



ID/DD: Intellectual and Developmental Disabilities

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- We need to use the information we have to set our priorities for research we will do in the future.
- Examples of possible future research can be to develop effective programs and inform policies that improve the health of people with intellectual and developmental disabilities.

## CDC Future Directions: Training and Tools

- **Develop evidence-based training and tools to educate and empower individuals, caregivers, and healthcare providers**



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- Finally, CDC and our partners can work together to develop tools that help educate and empower people with intellectual and developmental disabilities.
- Trainings can also be developed for caregivers and health care providers.
- And now I will turn it over to my colleague Dr. Susan Haverkamp.

## Education is Key to Better Health Care for People with Disabilities



### **Susan M. Havercamp, PhD, FAAIDD**

*Associate Professor of Psychiatry and Psychology and Director  
Health Promotion and Healthcare Parity Program, Ohio State University Nisonger Center, and  
Past President, American Association on Intellectual and Developmental Disabilities (AAIDD)*



U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

My name is Susan Havercamp. I work at the Ohio State Nisonger Center. I will talk about improving health care for people with disabilities. I am honored to be here.

Support for this training comes from the Centers for Disease Control & Prevention through the CDC Cooperative Agreement Number 5U59DD000931-02. The contents of this presentation are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.



Thank you to the CDC for supporting the work that I am presenting today. The CDC funded this project, but this presentation is my own work. The CDC may not agree with everything I say.

## Healthcare for People with Disabilities

- **25% of U.S. adult population has a disability**
- **As a group, people with disabilities have high needs for health care**
  
- **People with disabilities report**
  - Difficulty finding able and willing healthcare providers
  - Providers do not take the time to listen, or respect them
  
- **Healthcare providers report they are unprepared and uncomfortable caring for patients with disabilities**

Drainoni ML, Lee-Hood E, Tobias C, et al. *Journal of Disability Policy Studies* 17.2 (2006): 101-115

Holder MH, Waldman B, and Hood H. *International journal of oral science* 1.2 (2009): 66

Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. *MMWR* 2018;67:882–887

Shakespeare T, Iezzoni LI, and Groce NE. *The Lancet*, 374(9704), 1815–1816

One in every four Americans has some kind of disability. There are lots of different types of disabilities.

People with disabilities say that doctors and other health workers don't listen.

Health workers say they don't know how to care for patients with disabilities.

# Barriers to Health Care for People with Disabilities

## HEALTH ENVIRONMENT

Absence of disability standards in provider training  
Insufficient data on the health of people with disabilities  
Lack of inclusive health promotion programs

## HEALTHCARE SYSTEM

Scheduling constraints  
Payment and Reimbursement issues  
Lack of age appropriate services and supports

## CLINICAL PRACTICE

Inaccessible office and equipment  
Lack of staff training  
Communication barriers

## PROVIDER

Lack of disability training  
Incomplete knowledge  
of care coordination  
Poor attitude

Robinson, A.C. (2018). *Barriers to Health Care for People with Disabilities* [Infographic]. Adapted from [nisonger.osu.edu/wp-content/uploads/2018/07/Barriers-to-Health-Care-for-People-with-Disabilities.png](https://www.nisonger.osu.edu/wp-content/uploads/2018/07/Barriers-to-Health-Care-for-People-with-Disabilities.png)

People with disabilities face many barriers to good healthcare.

1. Students don't learn about people with disabilities.
2. Not having a ride makes it hard to get to appointments. Not having a lot of money makes it hard to pay healthcare bills.
3. Health offices aren't designed for patients with disabilities.
4. Health workers think all people with disabilities have bad health

## Interprofessional Health Education Needs Disability Standards to Meet the Health Needs of This Population



### Supported by

- U.S. Surgeon General Call to Action (2001) and National Blueprint (2005)
- National Academy of Sciences reports on Disability in America (2007, 2018)
- National Council on Disability Report (2009)
- World Health Organization World Report on Disability (2011)

Scientists and experts agree that healthcare students should learn to treat all patients



## Education Is the Answer to Healthcare Disparities

### Examples of Training Programs That Work

➤ **LEND provides disability training for interdisciplinary health students**

- Funded by MCH

➤ **National Curriculum Initiative on Developmental Medicine creates intellectual disability content for use at medical schools**

- Supported by CDC, AADMD and Special Olympics



➤ **Limitations of these programs**

- Do not reach all students
- Rely on champions and funding

LEND: Leadership Education in Neurodevelopmental and Related Disabilities, [mchb.hrsa.gov/training/projects.asp?program=9](https://mchb.hrsa.gov/training/projects.asp?program=9)

MCH: Maternal & Child Health Bureau, Health Resources & Services Administration

AADMD: American Academy of Developmental Medicine and Dentistry, [aadmd.org](https://aadmd.org)

Some training programs do a great job of teaching students to care for people with disabilities.

These programs do not teach every student though.

## Investing in Training about Disabilities Could Better Prepare Healthcare Students

- **Must address health inequities for the future workforce to meet the needs of underserved populations, including people with disabilities**
- **Alliance for Disability in Health Care Education asked the question, “What do health care professionals need to understand about disability to provide quality care to patients with disabilities?”**
- **Drafted competencies for providing care to individuals with disability**
  - Desired knowledge, skills and attributes essential to providing quality health care to patients with disabilities

The Alliance for Disability in Health Care Education, [www.adhce.org](http://www.adhce.org)

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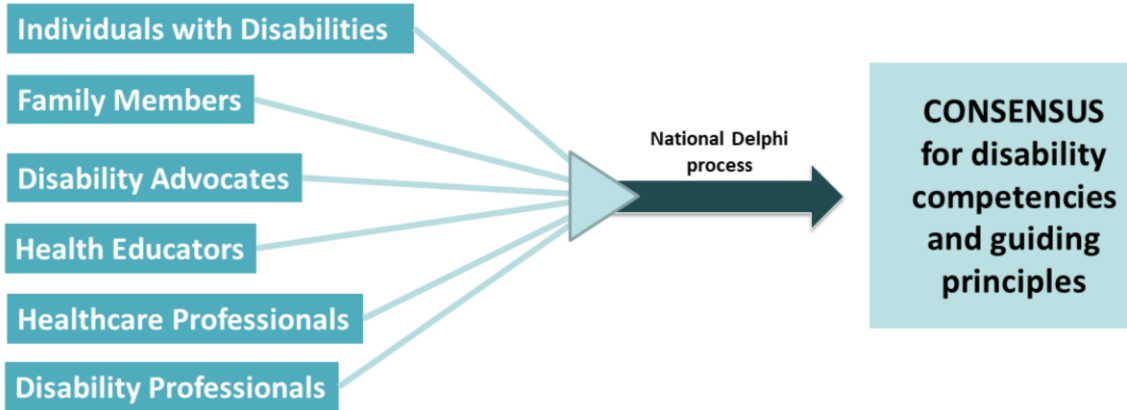
All healthcare students should learn about all kinds of patients.

A non-profit organization asked, “what do health workers need to know about disabilities?”

They made a list of things students should learn, called “disability competencies.”

Competencies are learning goals.

## The Ohio Disability and Health Program Sought Broader Input



[go.osu.edu/disabilitycompetencies](http://go.osu.edu/disabilitycompetencies)

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My research team asked many people what they thought. People with disabilities and their family were asked. Teachers and professionals were also asked. We changed the lists until everyone agreed that the list had everything that students needed to learn.

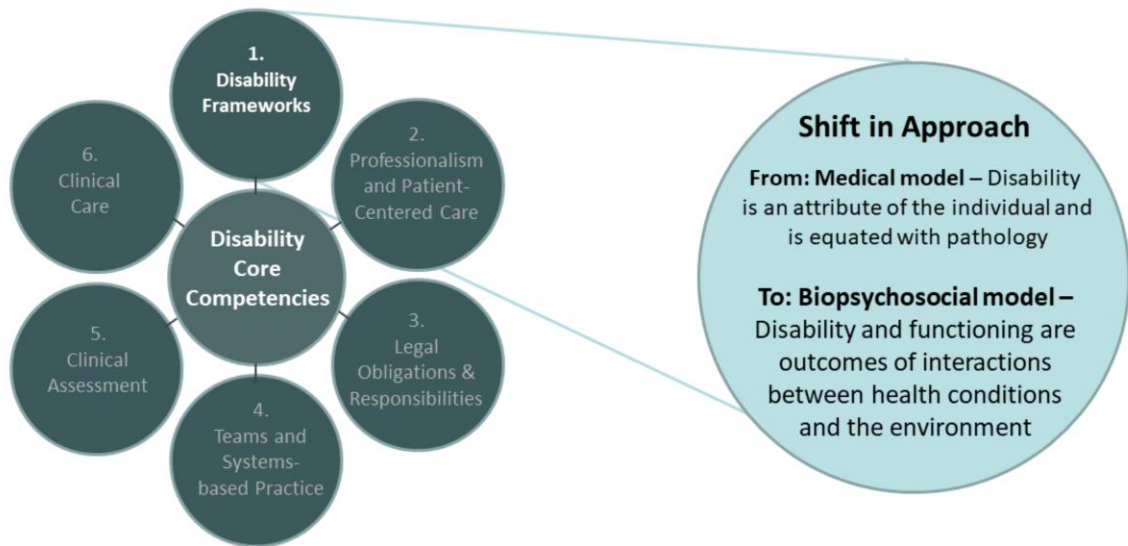
## Broad Consensus among Stakeholders



- **6 disability core competencies**
  - 47 sub-competencies
- **Interprofessional**
- **Cross-disability**
  - Intellectual disability
  - Sensory disability
  - Mobility disability

We came up with a new list that would work for all health workers, like doctors, nurses, social workers, psychologists.  
The list applies to people with all types of disabilities at all ages.  
There are 6 disability competencies.

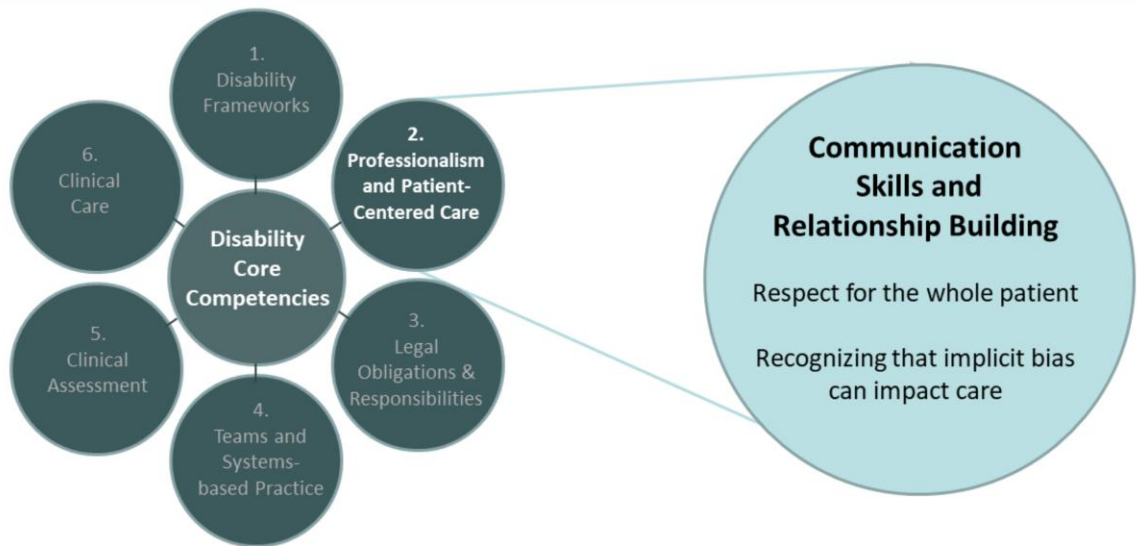
## Core Competencies on Disability for Healthcare Education



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Health care students need to know  
Disability is not a sickness. In fact, people with disabilities can be healthy.

## Core Competencies on Disability for Healthcare Education

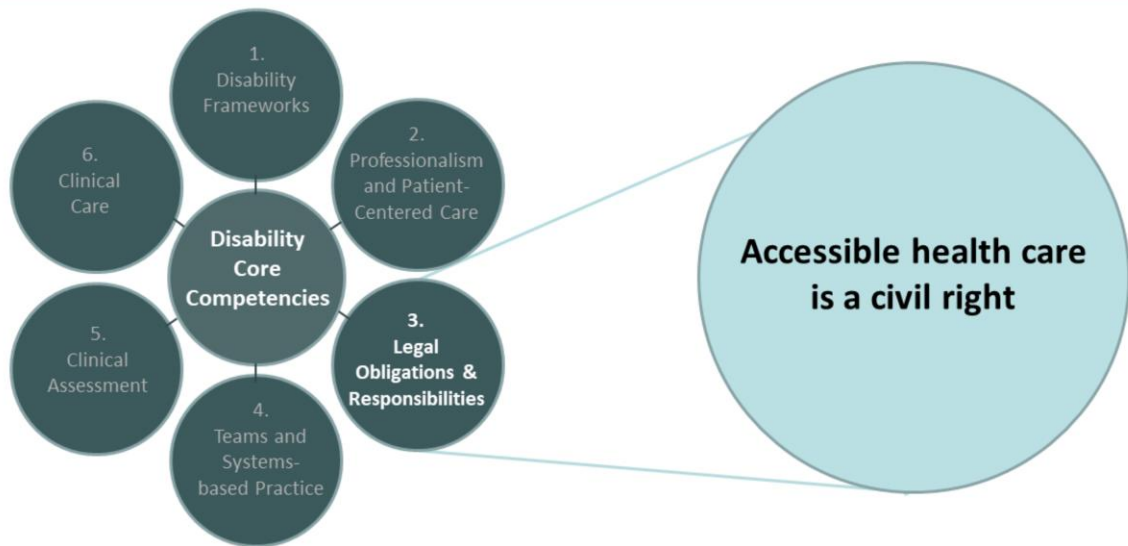


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Health care students need to learn

2. How to speak clearly. It is important to treat all patients with respect.

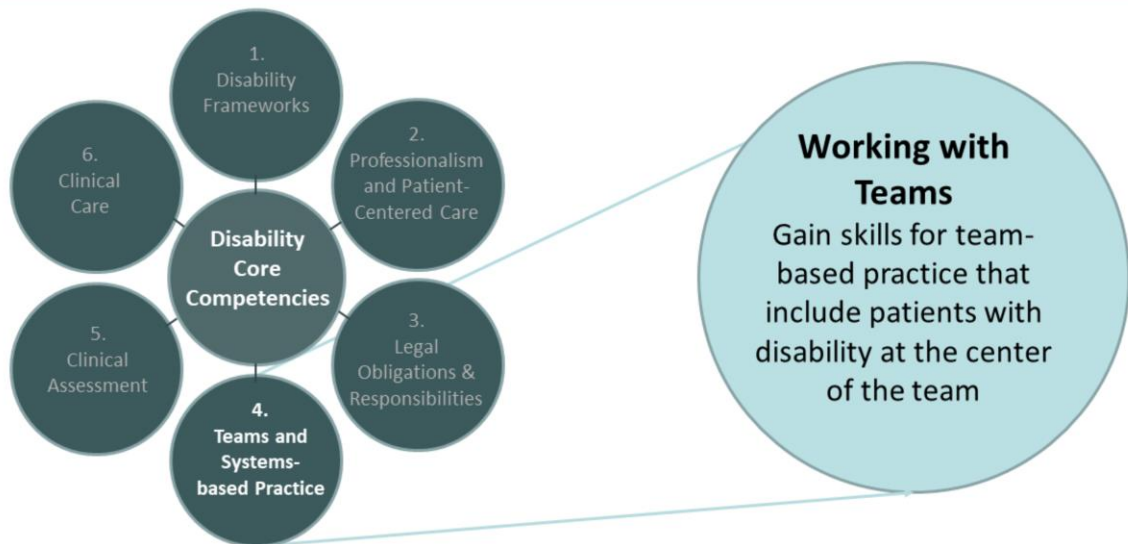
## Core Competencies on Disability for Healthcare Education



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Health care workers need to know that  
3. Everyone has a right to accessible healthcare.

## Core Competencies on Disability for Healthcare Education



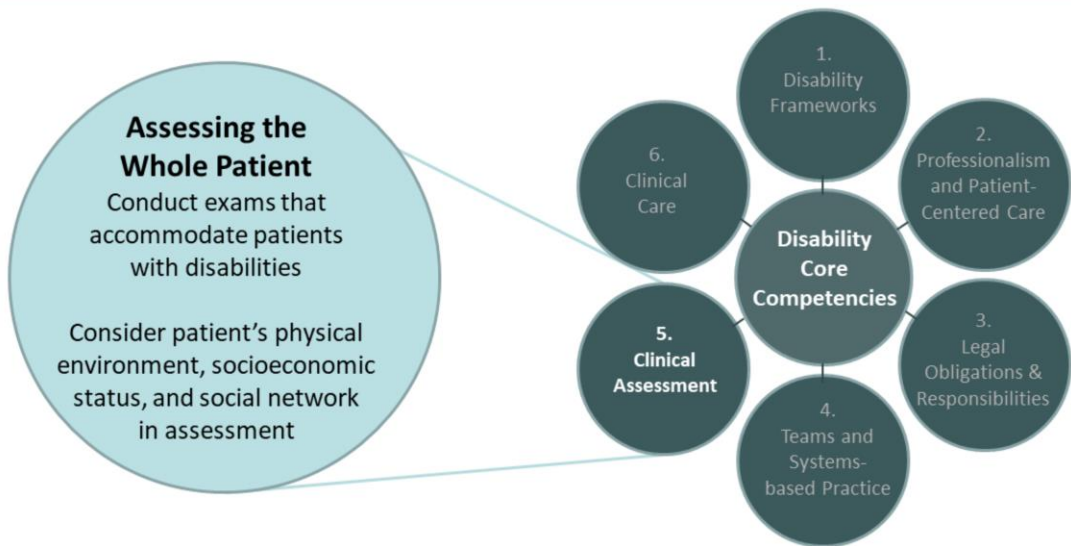
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Students should learn

4. to work as a team with other health workers. The patient should be at the center of the team.



# Core Competencies on Disability for Healthcare Education



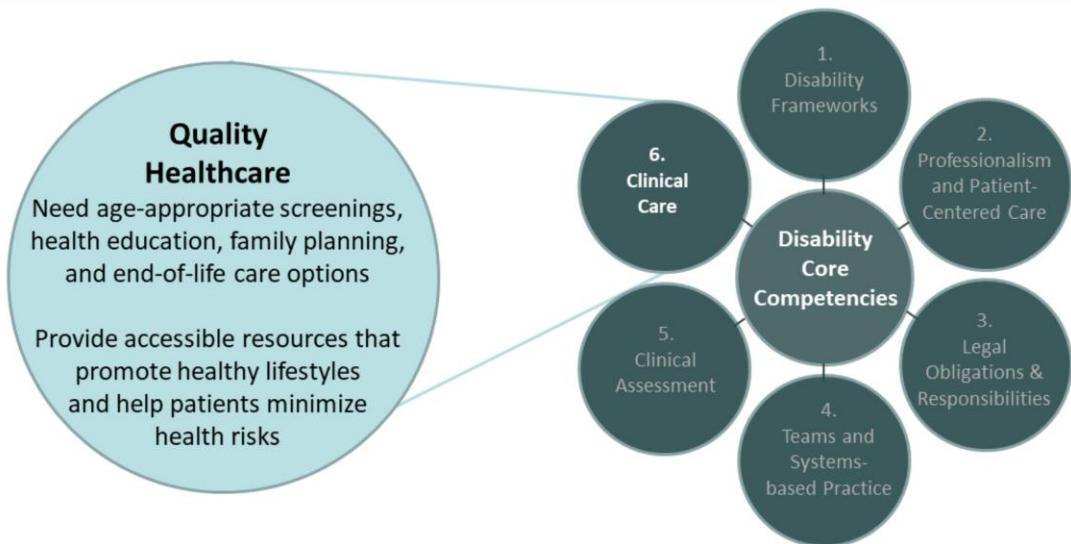
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Students should learn how

5. To do health exams with patients with disabilities.

Remember to think about the whole person, not just their disability

## Core Competencies on Disability for Healthcare Education



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Students need to understand that

6. All patients need health information and good health care

People need different information as they get older. They might need information about sex, starting a family, or making decisions about dying.

Remember to help all patients make healthy choices.

## Students Value Disability Training Opportunities More Comfortable with Patients

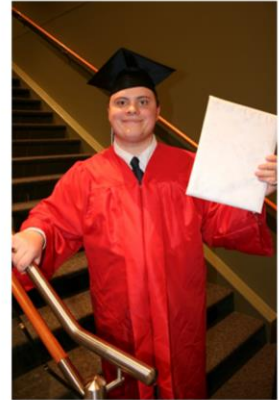
*"I am more comfortable and less awkward when seeing patients with disabilities because I learned it doesn't have to be the focus of the encounter."*



When students get disability training, they say they feel more comfortable treating patients who have disabilities.

## Students Value in Disability Training Opportunities Recognizing Personal Bias

*"I think it is easy to make certain assumptions, consciously or subconsciously, about people with disabilities that can only really be dispelled by interacting with individuals with disabilities."*



When students get to know people with disabilities, they learn to not judge what people can or can't do

## Students Value in Disability Training Opportunities Increased Understanding



*"The best takeaway that I had from the encounter was that people with disabilities want their medical concerns to be addressed in a direct and straightforward way just like any other patient."*

After disability training, students say  
Treat all patients with respect  
Focus on why the person came to the doctor, not their disability.

## We Must Include Disability Competencies in Professional Standards for Accreditation and Licensure



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Students should be required to learn about disabilities. This will be a game changer.  
ALL health care students will be ready to give good care to all patients.

## Nothing About Us Without Us



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I believe that we can improve health care for people with disabilities.  
It has been a pleasure to talk with you today  
Thank you!

# All Means All: Health Care for People with Disabilities



## Liz Weintraub

*Senior Advocacy Specialist and  
Host of Tuesdays With Liz: Disability Policy For All!*  
Association For University Centers On Disabilities (AUCD)



U.S. Department of  
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- I have an Intellectual disability and never went to college.
- Its important to have a person with Intellectual Disability on this panel.
- I hope today we start making health care better for people with disabilities by using the voices of people with Disabilities.



## NOTHING ABOUT US ... WITHOUT US

- **6.5 million people in the United States have an intellectual disability**
- **We have input on how to make the medical system work for us**
- **Our voices are important**
- **People with intellectual disability are people**



- My favorite saying is nothing about as without us meaning that if something is involving me then I deserve to be in that meeting
- Please do not go through the doctors or others when you're talking about my health
- We are people so treat us like that

## Keeping People with Disabilities Healthy Is Important



- **Right to be healthy just like anyone else**
  - Find care in our own community
- **People with disabilities get sick more often**
- **Deserve the chance and dignity to get better**
- **Not dead yet**

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- All people and that includes people with disabilities have the right to be healthy.
- When we get sick and need to see the doctor, we have the right to see a doctor that is right for us.
- A lot of people with disabilities get sick more often than the general population , because of our disability, and people deserve the chance to get better.

## People with Disabilities Should Know about Their Health

- **Nothing about US ... without US**
- **Complicated issues need to be explained in plain language**
  - Important to take time to explain in a way that makes sense to us
- **We decide who is the right provider for us**



- I am the patient, and that means that I would appreciate if the doctor would talk directly to me.
- Doctors need to include people with disabilities in the talk about their health even if it is hard to hear and must use plain language.
- We have the right to decide which doctor or provider makes the most sense for us.

## Privacy and Choice about Information Sharing Is Important

- WE have the RIGHT to decide WHO to share information with
- WE have the RIGHT to decide WHO to attend appointments
- But wait ... Does ALL mean ALL
- Guardians take away people's rights from them



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- I might not want everyone to know everything about me and my health care.
- Some appointments I don't want or need my husband to come with me. He might not want me to come with him to his appointments.
- We all have rights. If people with disabilities have guardians, they take away our rights.

## People with Disabilities Have Sex

- Sex is part of being a human being
- Know about it
- Can have it

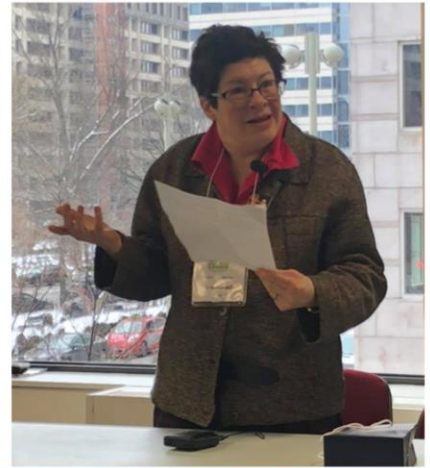


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- We deserve the right and the chance to enjoy having sex just like any other adult.
- The medical world is part of supporting this with good and clear information

## People Are In Control of Their Own Health

- **It's MY health so I AM in control**
- **It is not a question of if I can be in control, I demand to be**
- **Nothing about ME without ME**



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- People with Intellectual disabilities deserve the right and dignity to be in control and make decisions.
- Note that, I didn't say by ourselves. I don't believe that anyone makes decisions about their own health care on their own. We all need help.

## Resources

**National Independent Living Council (NICL)**

[www.ncil.org](http://www.ncil.org)

**Universality Centers on Excellence and Developmental Disabilities (UCEDD)**

[www.AUCD.org](http://www.AUCD.org)

**Local self-advocacy groups are great places to find advocates  
ready to partner to make health care work for  
people with intellectual disabilities**

[www.sabeusa.org](http://www.sabeusa.org)

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- Sex Ed for People with IDD: Easy Read Edition
- Each UCEDD has a Consumer Advisory Committee that includes leaders in your state who have Intellectual disabilities
- Find a group near you

## Inclusive Health: Creating Health Justice for People with Intellectual Differences



**Timothy Shriver, PhD**  
Chairman, Special Olympics

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- Today I will speak to you about the need for health equality.
- Everyone should have access to quality health services.
- No one should be left behind.





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- Here's my inspiration. Jacob Kerr, a Special Olympics athlete from Alaska, made a positive impact on his health. After finding out he was going to compete in the 2018 USA Games in Seattle, Jacob wanted to become the best athlete he could be and signed up for an 8-week fitness program.
- Before he started the program, Jacob had high blood pressure and was overweight. He had 16 cavities, his vision was 20/100 and he didn't have glasses. He went to a doctor and got on medication.
- He wanted to get healthier and by the end of the training program he lost 16 pounds and his blood pressure dropped from 180/120 to 139/90. By the time he went to the USA Games, he lost 30 pounds, was off his blood pressure medication, and was able to compete at his best.
- While you may know that Special Olympics provides opportunities for year-round sports training, you might not know about our health work. I'll be highlighting that work today. Oftentimes, our athletes do not come to us in great shape in terms of their health.
- How can our athletes perform when they have pain, preventable conditions and chronic diseases that are unrecognized and untreated?

## Why Did a Sports Organization Get Involved with Health?

**People with intellectual disabilities** are a **forgotten population** creating gross unmet **disparities** in terms of their **health status** and basic protections.



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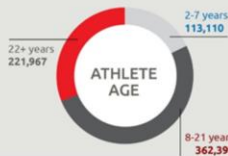
- Special Olympics is a sports organization that believes everyone should have access to quality health services.
- In this photo, my mom Eunice joins Loretta Claiborne in thanking United States Senator Ted Stevens from Alaska who fought for funding for Special Olympics.
- Loretta Claiborne has run many marathons and is a champion for individuals with intellectual differences.
- On average, people with intellectual disabilities die 16 years earlier than the rest of the population.

# Special Olympics Impact Across the United States

## SPECIAL OLYMPICS 2018 REACH REPORT

### ATHLETES

**700,000** 



### COMPETITIONS

**30,000**

UNIFIED  
**8,275**



**82 COMPETITIONS / DAY**

**3 COMPETITIONS / HOUR**

### HEALTH MESSENGERS

**980**

ATHLETE LEADERS  
TRAINED AS HEALTH  
ADVOCATES



### HEALTH VOLUNTEERS

**118,831**

BASED ON A SURVEY OF  
170 TRAINED PROFESSIONALS

**91%** Agree that the  
SO training improved their  
ability to communicate with  
people with ID

**93%** Agree that they  
will be able to provide better  
care for patients with ID



### FAMILY LEADERSHIP

FAMILY LEADERS

**13,290**

FAMILY MEMBERS  
EDUCATED ON THE  
HEALTH NEEDS OF  
ATHLETES



### US ATTITUDES DATA

FROM APPROX. 13500 RESPONDENTS:



**87%** Agree that people with ID  
have a **right to access healthcare**

**87%** Agree that people with ID  
should have the **same access to  
health services**

**64%** Agree that people with ID  
are **capable of describing symptoms  
to a doctor**

**9%** of people agree that a **person  
with ID will receive worse healthcare**  
than a person without ID in their community

- For over 50 years, Special Olympics has been changing the way the world views inclusion.
- We have a Program in every state, have nearly 120,000 health volunteers and 1,000 athlete leaders trained to talk about our work in health.
- According to a recent survey, nearly 90% of people agree that people with ID should have the same access to health services.


## In The United States, On Average ...




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- Unfortunately, Jacob's story is just one of the stories I want to share.
- In the US, we have 700,000 athletes with ID and 135,000 coaches.
- On an average team of Special Olympics athletes ...

## On Average U.S. Special Olympics Team of 10 Athletes...

 **8** are overweight or obese


 **7** have significant problems with flexibility

 **4** need a new prescription for eyeglasses

 **2** have some kind of eye disease

 **3** will fail a hearing test

 **3** have low bone density

 **3** have untreated tooth decay

 **1** needs an urgent referral to a dentist

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Based on Special Olympics Healthy Athletes screenings occurring between 2017–2018, resulting in over 400,000 observations

- Many athletes are overweight or obese, find it hard to balance, need glasses or have eye disease, will fail a hearing test, have low bone density, have cavities or need to see a doctor immediately.
- When these health problems aren't fixed, they can affect your entire life – your health, your chance to have a job, to go to school, to just live your life!
- These are serious health issues that CAN be addressed if everyone has the chance to go to a doctor and receive quality medical care.

## Inclusive Health: Solutions for Athletes

- ✓ Over 1 million **Healthy Athlete** screenings
- ✓ 31,135 athletes with **data on disparities**
- ✓ 53,247 participate in **year-round wellness** programming
- ✓ 980 **Athlete Health Leaders**



**73%** of athletes reported no mouth pain

**33%** of athletes had significant reductions in blood pressure

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- CDC and Special Olympics have been working together for over 20 years so that people with ID get access to quality health care.
- Special Olympics is giving our athletes the tools to advocate for their own health.
- Special Olympics has the largest data set on people with ID and has been collecting health data on our athletes since the mid-1990s. Since many of our athletes are in poor health, we started conducting health screenings, and have done over 1 million screenings.

## Inclusive Health: Solutions for Providers

- ✓ 13,290 **family members** as health advocates
- ✓ 118,831 **health professionals and students** trained
- ✓ **10%** of **medical school curriculums** changed



**93%** of professionals trained say they will be able to provide better care for patients with ID as a result of participating in training

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- In order to make inclusive health a reality, we are working to educate and involve health care providers and medical schools.
- We have trained nearly 120,000 health professionals and students at Special Olympics events on how to treat someone with ID.
- We have developed the NCIDM, National Curriculum Initiative on Developmental Medicine so that more medical schools will teach their students how to treat someone with intellectual and developmental disabilities.

## Inclusive Health: Solutions for Health Systems

- ✓ 326 **partnerships** increase access for people with ID to health services
- ✓ 55 **resources** and knowledge sharing through **online Center for Inclusive Health**

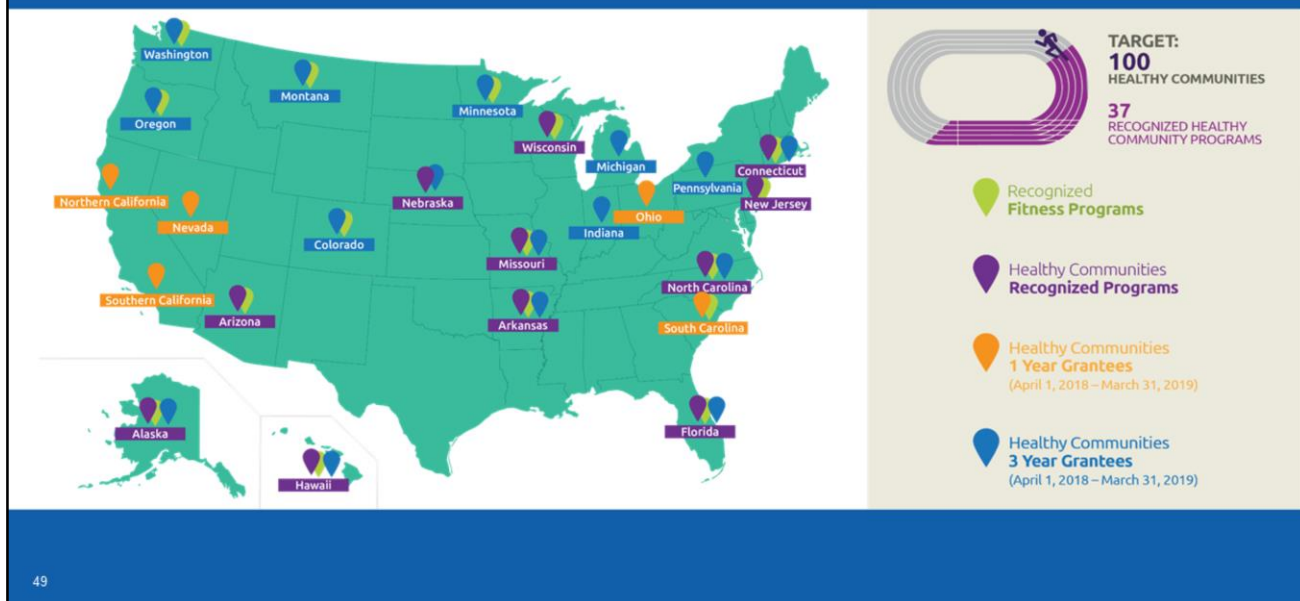


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- We have also reached out to partners to increase access to health care by bringing the health care to where the people are.
- Special Olympics Arkansas partners with the University of Arkansas Medical Services to provide free, on-site mammograms to Special Olympics' female athletes over age 40.
- We have created an online tool called the Center for Inclusive Health, where anyone can visit to learn how to make inclusive health a reality.



# Inclusive Solutions for Communities: Putting It All Together



- In 2012, the CDC funded a 6-state pilot of a new Special Olympics project called Healthy Communities to improve athletes' health and build a more inclusive environment at the local and state level. We created this to share with other states and help them be more inclusive in terms of health services.
- We encourage you to look into working to become a community of inclusion. There are several of these across the country and around the world.
- By talking about the health care problem for our athletes and teaching others how they can help, we are all making change happen.
- We have built Healthy Communities in 34 states, plus Puerto Rico. But we still have more work to do.

## Remaining Challenges

- **Lack of consistent, national-level longitudinal data for intellectual disabilities (ID) vs. not ID**
- **Quality measurement**
- **Incentivizing care appropriately**



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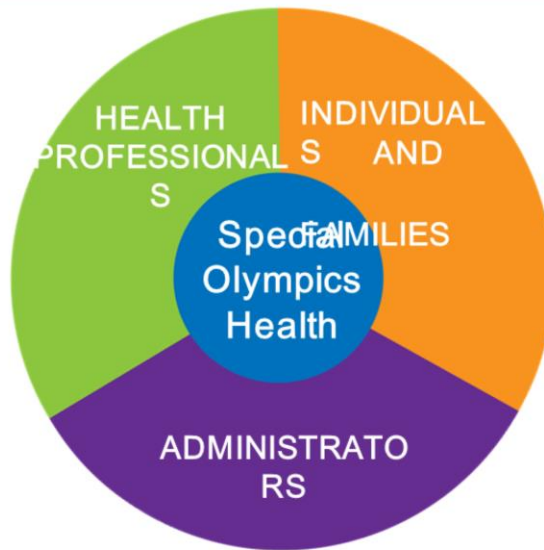
- As I mentioned, Special Olympics has done a lot in our 50 years, but we know from collecting data on our athletes, we can't make changes unless we have data.
- We don't know what good quality of care looks like for each disability. We need to understand that. And we need others to help us.
- Our health care systems need to offer incentives for people to be healthier.

# How We Can Advance Inclusive Health Together?

Take a course on  
treating people  
with ID

[learn.specialolympics.org/](https://learn.specialolympics.org/)

Endorse designation  
of people with ID  
as “medically  
underserved”



Get screened  
at Healthy  
Athletes

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- We can make inclusive health happen. But we must do it together.
- We need to continue to teach and train health professionals on how to treat people with ID. We can bring the community and policymakers together. We can connect families to medical experts.
- The answer is making sure every doctor, dentist and nurse has training. We want more athletes to get screened at a Healthy Athletes screening and want both the athlete and caregiver to demand equitable care
- We need the government to support the term that people with ID are “medically underserved” so that they get access to more support and services.

Thank you!



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Thank you.