Introduction to session on addressing gaps in health care for individuals with intellectual disabilities.
• 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.
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.
• 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.
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.
• 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
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.
• 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 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.
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.
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 Havercamp.
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.
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.
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.
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.
Scientists and experts agree that healthcare students should learn to treat all patients.
Some training programs do a great job of teaching students to care for people with disabilities. These programs do not teach every student though.
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.
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.
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.
Health care students need to know
Disability is not a sickness. In fact, people with disabilities can be healthy.
Health care students need to learn
2. How to speak clearly. It is important to treat all patients with respect.
Health care workers need to know that
3. Everyone has a right to accessible healthcare.
Students should learn
4. to work as a team with other health workers. The patient should be at the center of the team.
Students should learn how
5. To do health exams with patients with disabilities.
Remember to think about the whole person, not just their disability
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.
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.
After disability training, students say
- Treat all patients with respect
- Focus on why the person came to the doctor, not their disability.

“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.”
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.
I believe that we can improve health care for people with disabilities. It has been a pleasure to talk with you today. Thank you!
I have an Intellectual disability and never went to college.

It’s 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.
• 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
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.
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.
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.
• 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 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.
• 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
• 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.
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?
• 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.
• 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.
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 ...
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.
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.
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.
• 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.
• 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.
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.

Remaining Challenges

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