

U.S. Department of Health and Human Services

Disability and Health and Health-Related Quality of Life and Well-Being

Thursday, August 11, 2016

**WebEx Producer:** Good afternoon and thank you for joining the Healthy People 2020 Progress Review webinar. You are now on listen-only mode. Please use the Q and A feature on the right-hand side of your screen to submit any questions. Your questions will be answered at the end of the webinar. I would now like to introduce the Acting Assistant Secretary for Health in the U.S. Department of Health and Human Services, Dr. Karen DeSalvo.

## **Opening Remarks**

**DR. DeSALVO:** Well, hello, and thank you everybody for joining us for today's Healthy People 2020 Progress Review webinar. During these webinars, we have the chance to focus on an issue of public health importance that is supported by two Healthy People 2020 topic areas. So over the next 90 minutes, we will explore Disability and Health and Health-Related Quality of Life and Well-Being. This webinar will focus on maximizing inclusion and participation to improve outcomes. We will review where we are as a nation in meeting these Healthy People 2020 goals, and more importantly, discuss what we are doing to achieve them.

Next slide.

I am delighted that we are joined today by senior officials from across the department who will share how Health and Human Services is working to support these topics. First, Dr. Charles Rothwell, the Director of the National Center for Health Statistics, will provide an overview of the most current data in these topic areas.

Next, we will hear how agencies across HHS are working to achieve the Healthy People objectives. First, we'll hear from Dr. Alison Cernich, the Director at the National Center for Medical Rehabilitation Research within the National Institute for Child Health and Human Development at the NIH. Then we will hear from John Tschida, Director of the National Institute on Disability, Independent Living, and Rehabilitation Research at the Administration for Community Living Next, from Dr. Georgina Peacock, the Director of the Division of Human Development and Disabilities and the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. And finally, Dr. Jennifer Madans, Associate Director for Science at the National Center for Health Statistics, will tell us about efforts to track and measure health-related quality of life and well-being. We will also have the chance to hear how Healthy People is being applied in the field from Dr. Meg Traci, Assistant Research Professor at The Montana Disability and Health Program.

Next slide.

Healthy People 2020 is a national agenda for improving the population's health and achieving health equity. Now in its fourth decade, it has grown tremendously over the years and remains at the forefront of current public health issues. It is one of the most enduring health promotion and disease prevention initiatives in the nation.

Healthy People tracks national data for federal, state, local, and non-governmental not-for-profit and academic stakeholders. Specifically, it's a set of measurable objectives with targets to be achieved by the end of this decade. Stakeholders are valuable contributors in the development of Healthy People 2020.

Next slide.

This slide shows the growth and development of Healthy People 2020. You can see that it has grown now to include more than 1,200 objectives in 42 topic areas. The overarching goals have also evolved over time to reflect the need to not only eliminate health disparities, but also to achieve health equity in addition to promoting quality of life across all life stages.

Next slide.

As I mentioned earlier, Progress Review webinars focus on two topics areas, and today we will cover the Disability and Health topic area along with Health-Related Quality of Life and Well-Being. Disability and Health is co-led by the CDC, ACL, and NIH. The Disability and Health topic area focuses on the health of people living with disabilities.

Disability is a part of human existence occurring at any point in life. Consistent with the World Health Organization's definition, disability is a single term that encompasses having an impairment, activity limitations, and participation restrictions. The prevalence estimates for disability are dependent on which data source is analyzed. According to the U.S. Census, more than 72 million Americans, or approximately 22 percent, have some type of impairment.

Next slide.

People with disabilities are less likely to receive recommended preventive healthcare services such as routine dental cleanings and cancer screenings. They're at high risk for poor health outcomes such as obesity, hypertension, fall-related injuries, and mood disorders such as depression. And they're more vulnerable to behaviors that put their health at risk, such as tobacco use and inadequate physical activity.

Next slide.

The last two iterations of Healthy People prioritized the health of people with disabilities because awareness of the diverse populations living with disabilities in the United States is fundamental to increasing inclusion and participation. Individuals' disabilities are influenced by their communities, including both social and physical environment. To be healthy, all individuals living with disability must have opportunities for meaningful daily activities that add to their growth, development, fulfillment, and overall quality of life.

Until recently, people with disabilities have been overlooked in public health surveys and data analyses and health reports, making it difficult to raise awareness about health status and existing disparities. Including people with disabilities in health surveillance and health promotion interventions aimed at improving cross-sector health determinants can lead to more direct health benefits and reduce healthcare costs.

In communities across the U.S., there are innovative public health efforts underway to improve health outcomes and quality of life for children and adults living with disabilities. The best of these programs include those with disabilities and their families as partners in program planning and evaluation, like the one we'll hear about later, which is happening in Montana.

Expansion of public health programs serving persons living with disabilities will have the primary benefit of reducing disparities, stigma, social isolation, health complications and functional loss, and with further benefit of reducing healthcare costs.

Next slide.

The second topic area covered during today's webinar is Health-Related Quality of Life and Well-Being. This topic is multidimensional and includes domains that relate to physical, mental, emotional, and social functioning beyond direct measures of population health, such as life expectancy and causes of death, and focuses on the impact of health status on quality of life.

Well-being assesses the positive aspect of a person's life such as positive emotion and life satisfaction. And well-being is a state where one maximizes physical, mental, and social function in the context of supportive enrollment to live a full satisfying and productive life.

With that, I will turn it over to Charles Rothwell, the Director of the National Center for Health Statistics, to review the most current data in these topic areas.

### **Presentation - Charles Rothwell**

**DR. ROTHWELL:** Thank you, Dr. DeSalvo.

Today we're going to be talking about the progress of Healthy People 2020 objectives in two topic areas, Disability and Health and Health-Related Quality of Life and Well-Being. We're going to go through a lot of data slides, and it's going to go very quickly. Don't worry about it. There's going to be a set of summary slides at the end with the main topics. So I think just hold on to your seat, and we'll go through this.

Next slide.

For the Disability and Health topic area, there are 21 measurable objectives. Five objectives have met their target and another two are improving and moving toward their target. Seven objectives are showing little or no detectable change, and three are actually moving away from the targets based on the most recent data. For the Health-Related Quality of Life and Well-Being topic area, there are two measurable objectives. Both have baseline data only.

Next slide.

Next, we'll go into detail on the selective objectives of Disability and Health topic area and examine data systems that collect data on disability. Then we'll look at objectives that monitor health promotion programs, barriers to primary care, participation in education, unemployment, and serious psychological distress among adults with disabilities.

Next slide.

The definition of adult with disability is based on a set of six questions that the American Community Survey, the ACS, which is sponsored by the Bureau of Census, uses to identify persons with disabilities. A response of yes to any of these questions indicates that the person has a disability. These questions cover six disability types, including hearing, vision, cognitive, ambulatory care, self-care, and independent living difficulty. The ACS questions have been

implemented in a number of major national health surveys and are recommended for use in other surveys and data collection systems.

Next slide.

Now, we'll look at the number of population-based data systems used to track Healthy People 2020 objectives that include the six disability questions I just mentioned in the American Community Survey. The objective has met and exceeded its target with 13 data systems using the ACS disability questions as of 2015.

So today, we will be reviewing objectives based on the data from several of these population-based systems, including the National Health Interview Survey; the National Health and Nutrition Examination Survey, or NHANES; the Medical Examination Panel Survey, or MEPS; or the CPS, the Current Population Survey.

Next slide.

Health disparities continue to persist by disability status for both healthcare access and health behaviors. For example, women age 50 to 74 years with disabilities were less likely than those without disabilities to receive breast cancer screening, 65.8 percent versus 72.2 percent. Adults with disability were twice as likely to be current cigarette smokers than those without disability.

Next slide.

Now, we'll look at the number of state health promotion programs for persons with disabilities. The count is obtained through the periodic assessment by staff of the National Center for Birth Defects and Developmental Disabilities at the CDC. The number of state and D.C. health programs that have at least one health promotion program aimed at improving health and well-being of people with disabilities has met the Healthy People 2020 objectives since 2012.

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The next slide shows the proportion of adults with disabilities experiencing barriers to receiving primary care in the past 12 months, and the data are collected through the National Health Interview Survey. Overall, there was little or no detectable change in this objective from 2009 to 2015.

Next slide.

For the next two slides, we'll look at data from Individuals with Disabilities Education Act, the IDEA database, from the Department of Education. The proportion of children age 2 years and under with disabilities who received early intervention services in home- or community-based settings have met the 2020 target.

Next slide.

The percent of students, age 6 to 21 years with disabilities who spent at least 80 percent of the day in regular classrooms, has improved from 56.8 percent in 2007-08 to 62.1 percent in 2013-14, although it's still well below the Healthy People 2020 target of 73.8 percent.

Next slide.

Next, we'll look at unemployment data for adults with disabilities from the Current Population Survey. Unemployment for adults with disabilities has decreased from 15.6 percent in 2009 to 14 percent in 2014, meeting the Healthy People 2020 target. Adults with less than a high school education were more likely to experience unemployment than other educational groups in 2009 and 2014. Hispanic and black adults were more likely to experience unemployment compared to white adults.

Next slide.

Now, this slide shows the proportion of adults with disabilities who experienced serious psychological distress in the last 30 days. Total serious psychological distress for adults with disabilities has shown no change between 2010 and 2015, 14.4 percent in both years. Older adults with disabilities were less likely to have experienced serious psychological distress compared with other age groups.

Next slide.

Now, we'll transition to the health-related quality of life and well-being topic area. The next slides will look at the Patient Reported Outcomes Information System, PROMIS measures. Data from PROMIS measures were collected in a special supplement to the National Health Interview Survey in 2010. The slide shows the four PROMIS questions on physical health. The questions cover overall self-reported physical health activities of daily living, fatigue, and pain. Responses are combined, and the data are then divided into two main categories, good or better physical health versus poor physical health.

Next slide.

Now, this slide, very similar to the last slide, shows the four PROMIS questions on mental health. Questions cover overall quality of life, self-rated mental health, satisfaction with social activities and relationships, and recent emotional problems. As we saw with physical health measures, responses to these four mental health questions are combined, and the data are also divided into two main categories: good or better mental health versus fair or poor mental health.

Next slide.

Now let's look at self-reported good or better physical mental health by disability status. And the data from this slide and the following slides come from the National Health Interview Survey of the National Center for Health Statistics. Adults with disability were less likely to report good or better physical and mental health compared to adults without disability. Interestingly though, adults with disabilities reported significantly better mental health than their physical health.

Next slide.

Next, we'll review the data for self-reported good or better physical and mental health by age. Younger adults have higher rates of self-reported physical health and mental health than older adults. However, the age gradient is much stronger for physical health than for mental health.

Next slide.

Now, this very involved slide shows self-reported good or better physical health by sex, race, ethnicity, and educational attainment. Men and Asian adults were more likely to report good or better physical health than their counterparts. Adults with less than a high school education were least likely to report good or better physical health compared to other educational groups.

Next slide.

Finally, we'll look at self-reported good or better mental health for adults by sex, race, ethnicity, and educational attainment. The last slide was just like this one. This is for mental health now. The results for mental health are very similar to what we saw for physical health. Men and Asian adults reported better mental health than their counterparts. Adults with advanced degrees were most likely to report good or better mental health compared to other educational groups.

Next slide.

So what does all this mean? Now the number of Healthy People 2020 objectives, based on the data systems that include ACS disability questions, has increased. The number of states with support for disability and health promotion programs has increased. The use of intervention services in community settings by children age 2 years and under with disabilities has increased. There has been an increase in the proportion of students age 6 to 21 years of age with disabilities who spend at least 80 percent of their day in regular educational classrooms; all good news.

Next slide.

There are more opportunities for improvement as disparities persist in unemployment of adults with disabilities by race, ethnicity, and educational attainment. Two objectives have shown little or no detectable change, including barriers to primary care and serious psychological distress for adults. However, each of these objectives have experienced a decrease in disparities based on the most recent data. So far in the decade, 7 out of 21 Healthy People 2020 disability and health objectives have reached their targets or are improving.

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Finally, here are some key takeaways for the health-related quality of life and well-being topic area. Overall, more than 75 percent of adults reported good or better physical mental health. The largest disparity in health-related quality of life was by disability status. Fewer than 40 percent of adults with disabilities reported good or better physical health, and only 50 percent reported good or better mental health.

Disparities persist by age, race, ethnicity, sex, education, as health-related quality of life was highest among younger people, Asian, and white adults, males, and adults with a college degree. Thank you very much.

**DR. WRIGHT:** Thank you, Mr. Rothwell.

At this time, I want to turn the webinar over to Dr. Alison Cernich. She's director of the National Center for Medical Rehabilitation at the National Institutes of Health. Dr. Cernich?

**Presentation - Alison Cernich**

**DR. CERNICH:** Thank you, Dr. DeSalvo for the introduction and Dr. Rothwell for the data presentation. In addition to highlighting progress, the data also help identify areas that need more work. The next set of presentations highlight a few program efforts related to some of the Disability and Health objectives presented in the data segment. The following program efforts are necessary to help drive the data and progress in the Disability and Health topic area.

Next slide.

The Disability and Health topic area's co-coordinated by three distinct programs within the U.S. Department of Health and Human Services, including the National Center for Medical Rehabilitation Research located within the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute on Disability Independent Living and Rehabilitation Research, and the National Center on Birth Defects and Developmental Disabilities.

Each agency takes a different approach to improving health, inclusion, and participation among people with disabilities. The National Center for Medical Rehabilitation Research identifies safe and effective approaches to improving and restoring health through research often conducted through universities or small businesses. NIDILRR identifies ways to improve health through group studies, often conducted at university-based rehabilitation research and training centers in conjunction with independent living centers. The National Center on Birth Defects and Developmental Disabilities modifies and translates ways to impact population health often through state health departments and universities in conjunction with national organizations.

The next three presenters are from these three agencies. They will highlight selected program efforts that are related to the topic objectives.

Next slide.

So I'm Dr. Alison Cernich. I'm the director for the National Center for Medical Rehabilitation Research referred to as NCMRR. This program resides, as I said, within the Eunice Kennedy Shriver National Institute for Child Health and Human Development at the National Institutes of Health. We have been in operation since 1990.

Next slide.

The mission of the NCMRR is to enhance the health, productivity, independence, and quality of life of people with physical disabilities. We do this through basic translational research, which can lead to clinical application or public health dissemination.

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One of NCMRR's main functions is to provide research infrastructure to the field to include big data initiatives; translation of technologies and devices for commercial use by people with disabilities; advancing technologies and treatment options; improving software use to model disability and enhance ability to treat; and improving clinical trials to raise the quality of evidence available regarding interventions for individuals with disabilities. We also sponsor training programs for physicians and allied health professionals in rehabilitation.

Next slide.

To achieve our mission, NCMRR funds several basic science research projects. Among them, we are currently funding a study to examine the effect of a novel social network intervention on stroke recovery. Each year, 795,000 adults have a stroke. This study will help identify social and emotional supports that influence positive health outcomes among these adults using big data. The study is related to objective DH-17, which is increase the proportion of adults with disabilities who report sufficient social and emotional support.

Next slide.

In addition, we fund other studies related to objective DH-18, reduce the proportion of adults with disabilities who experience serious psychological distress. One study will evaluate a new method of teaching people with TBI to regain control of a problematic symptom of anger and irritability with expected benefits on their emotional well-being and ability to cope with living in the community. Another study will evaluate the effect of treatment for anxiety among intensive care unit patients on their engagement and rehabilitation while hospitalized. These projects may help address some of the mental health disparities among people with disabilities highlighted earlier by Director Rothwell.

Next slide.

NCMRR research typically culminates with published findings. This slide shows the front cover of a recently published manuscript highlighting the development of an instrument called Neuro-Qol. Neuro-Qol, or quality of life and neurological disorders, is a measurement system that evaluates and monitors the physical, emotional, and social effects experienced by adults in children living with neurological conditions.

This work relates to the objective DH-18, which states reduce the proportion of adults with disabilities age 18 and older who experiences serious psychological distress, as well as Health-Related Quality of Life and Well-Being objectives 1.1 and 1.2, increase the proportion of adults who self-report good or better physical or mental health. This and other research can enhance the lives to people with disabilities.

I thank you for your attention, and I would like to introduce our next speaker, Mr. John Tschida.

### **Presentation - John Tschida**

**MR. TSCHIDA:** Thank you, Dr. Cernich.

Good afternoon. I am John Tschida, director of the National Institute on Disability, Independent Living, and Rehabilitation Research, also known as NIDILRR. This program sits within the Administration for Community Living within the U.S. Department of Health and Human Services. Formally with the Department of Education, NIDILRR has been operating since 1978.

Next slide.

The mission of NIDILRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. So you can see there's both an individual and a systems level component to our

Microsoft Office Userwork, which we address through research and development, knowledge translation, and capacity building.

Next slide.

Aligned with our mission, independent living has five community living principles; as you can see here, self-directed choice, community membership, tailored services and support, relationships that provide positive social and emotional support, and a home that is one's own. This really is a person-centered framework that values strongly individual choice and control.

Next slide.

To achieve our mission, or help achieve our mission, NIDILRR funds several projects in coordination with Centers for Independent Living or CILs. CILs provide five core functions: information and referral; peer counseling; independent living skills training; individual and systems advocacy; and their newest core service added in 2014, services that facilitate transition from nursing homes with other institutions to the community, or provide assistance to those at risk of entering institutions; and facilitating transition of use to the post-secondary life as well. These services support objective DH-13, increasing participation in community activities.

The CILs, governed and run by and for people with disabilities, often serve as a first call for help for individuals with disabilities of all ages. There are more than 350 nationwide. An example of a wonderful initiative would be one that these CILs in eight states are implementing, a program called Living Well with a Disability. This program has been supported by the CDC and NIDILRR to promote health among people with disabilities and will be featured later in our webinar.

Next slide.

As Dr. Cernich mentioned, NIDILRR funds a number of projects carried out through university-based rehabilitation, research, and training centers, or RRTCs. These RRTCs conduct coordinated and integrated research to improve rehabilitation approaches and service-delivery systems; alleviate or stabilize disabling conditions; or promote maximum social and economic independence for persons with disabilities. There's also a strong training and technical assistance component to the RRTCs as well.

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For example, through the RRTC on developmental disabilities and health, we support a program called HealthMatters, funded by both NIDILRR and the National Institute on Child Health and Human Development. HealthMatters is a program designed to improve health among people with intellectual and developmental disabilities. To date, the HealthMatters community academic partnership team has trained over 2,000 instructors in 20 states and 5 countries to initiate programs that will help people with intellectual and developmental disabilities become more physically active and make healthier food choices to reduce the onset of chronic health conditions such as diabetes, hypertension, and cardiovascular disease.

As you can see on the bottom of the slide, the HealthMatters programs addresses three Healthy People 2020 topic areas. And actually in these three domains, they address eight specific related objectives.

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As part of a multistate scale-up program, four states that you see here have deployed the HealthMatters intervention to examine the challenges to successfully replicating HealthMatters in community settings and understand the conditions and activities that contribute to its effective adoption. A scale-up logic model will be developed detailing the necessary components to achieve systemic reach and impact among a population that often receives lifelong community-based support and healthcare services within complex and diverse systems across the United States. The HealthMatters program continues to grow, and we look forward to providing future updates.

I thank you for your time and attention, and our next speaker will be Dr. Georgina Peacock.

### **Presentation - Georgina Peacock**

**DR. PEACOCK:** Thank you, and good afternoon. I'm Georgina Peacock, the director of the Division of Human Development and Disabilities of the National Center on Birth Defects and Developmental Disabilities in Atlanta.

Next slide.

This slide shows four images depicting our center's mission, to promote the health of babies and improve the health of children and adults with birth defects, blood disorders, and disability. The Division of Human Development and Disability and the Disability and Health Program sit within this center. The Disability and Health Program has been operating since 1988 to improve the health of people with disabilities.

Next slide.

To achieve our mission, we partner with state health departments. This partnership supports objective DH-2.1, which is to increase the number of states with health promotion programs for people with disability. This slide shows a map of the United States indicating 19 states who have health promotion programs for people with disabilities. Their projects address cardiovascular disease, hypertension, diabetes, and their related risk factors such as tobacco use, obesity, physical activity, nutrition, and healthy weight.

Next slide.

To address these health issues, states like South Carolina have worked towards removing barriers to health care. South Carolina's program staff visited 150 primary care sites to assess their capacity to serve people with disabilities. Based on the assessment, several recommendations for modifying these facilities were made. Several sites followed up on recommendations such that a third of them made changes to their parking areas, ramps, door handles, restrooms, and signs.

This slide shows before and after pictures of a facility that added an accessible parking area for people with disabilities. This project relates to objective DH-4, to reduce the proportion of adults with disabilities age 18 years and older who experience delays in receiving primary and periodic preventive care due to specific barriers. By removing barriers to health care such as these, people with disabilities can receive better routine health care.

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NCBDDD also partners with organizations like the National Association of County and City Health Officials who work with local health departments to increase the inclusion and participation of people with disabilities and public health efforts. For example, Kent County, Michigan created an emergency preparedness citizen's stakeholder group that included people with disabilities and also created inclusive emergency preparedness training modules covering fire safety, cardiopulmonary resuscitation, or CPR, first aid, and emergency response team or ERT training. Including people with disabilities and an emergency response efforts can result in better planning and preparedness with potentially fewer casualties during an emergency.

This work relates to objective DH-13, which is to increase the proportion of adults with activity limitations age 18 years and older who participate in leisure, social, religious, and community activities, as well as preparedness objectives 11, 12, and 13, which focus on household emergency preparedness.

Next slide.

Within our division, the disability program also recently partnered with the National Association of Chronic Disease Directors, or NACDD, to launch a healthy community's project to reach people with disabilities. This project aligns with the objective DH-8, reducing barriers to local health and wellness programs, and DH-13 for increasing community participation.

Ten communities in five states have received about \$22,000 to increase access and opportunities for healthier eating and physical activity among people with disabilities who live in those communities. The 10 local communities are Sioux City and Carroll County, Iowa; Helena and Butte County, Montana; Cattaraugus and Syracuse County, New York; Adams and Marion County, Ohio; and Benton and Umatilla, Oregon. Subject matter experts in the National Center on Health, Physical Activity, and Disability, or NCHPAD, are providing technical support to this project.

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In addition to these new 10 community projects, as mentioned earlier, a more detailed description of the Living Well with a Disability, a longer standing local community intervention to produce health, quality of life, and well-being, will be presented a little later.

Next slide.

These and other program efforts presented today are intended to work synergistically. Together with you, we can build greater awareness about the needs of people with disabilities, thereby increasing inclusion and participation in public health efforts to improve their quality of life and well-being and ultimately reduce health disparities among people with disabilities as indicated by the data presented earlier.

Next slide.

For more information about the Disability and Health topic area and its objectives or examples of programs related to these objectives, please contact Lisa Sinclair or Mike Fox. This slide provides their email addresses.

Thank you, and now I will turn it back to Dr. Wright.

**DR. WRIGHT:** Thank you very much, Dr. Peacock. At this time, I'd like to transition the webinar to Dr. Jennifer Madans. Dr. Madans is the Associate Director for Science at the National Center for Health Statistics. Dr. Madans?

### **Presentation - Jennifer Madans**

**DR. MADANS:** Thank you, Dr. Wright.

And I'm going to change course here a little bit because I'd like to talk a little bit about some of the measurement issues that are related to the concept of health and disability. Next slide. First, a little bit about NCHS, although I think anyone who has been attending these webinars probably is already very familiar with the agency. But just to say that the primary/only mission of NCHS is to monitor the nation's health by collecting, analyzing, and disseminating health data. And this is not only for the total population but also to focus on comparisons across time, populations, providers, and geographic areas. Many of the data that you've already heard today are coming from NCHS data systems.

In order to be able to produce that data, we also have a major function related to methodology. We need to ensure that the data are comparable, reliable, and valid, and so we undertake a fair amount of methodological research to improve the methods that we're using for the collection of health statistics. And that's what I'd like to talk about today.

Next slide.

NCHS is also one of the named federal statistical agencies. You can see the other agencies on this slide. Some of them are very familiar to you. We work very closely with these agencies in terms of methodological work, but also to maintain some consistency in data collections, some of that you've heard about the work on the ACS for the disability measures that is used in other surveys.

Next slide.

Then just very briefly, this is a list of our major data collections systems. Again, you have heard about these data collection systems not only in this webinar, but I'm sure in many of the other webinars.

Next slide.

So how does this all relate to Healthy People? Well, as Dr. DeSalvo said earlier, Healthy People really is designed to identify where we as a nation want to go in terms of our health goals and to identify those goals and those objectives. But it also has a major monitoring function, and I think that's where the two agency programs come very closely together. NCHS is primarily designed to do monitoring, and Healthy People has this major monitoring function.

It does that monitoring function by looking at a very large number of specific objectives and targets, which is important in trying to determine exactly what areas that we need to focus on. But Healthy People has also traditionally included overarching goals. And I think there's just a general feeling that where we want to go in terms of this program, in terms as a nation, in terms of health, is more than the sum of the individual parts and the individual indicators of Healthy People. We really want to be able to talk about the health of the nation. And there is the challenge. How do we create

overarching measures that encompass the full range of health that Healthy People is trying to set goals and targets for?

Next slide.

And as a methodologist and someone interested in measurement issues, where we usually start is back with the definition. And that is really where our problems begin in the area of health. The term "health" is something that we all intuitively understand. We think we are talking about the same thing when we're talking about health and it turns out that's not the case. This is a very complicated, multi-factored concept, and there are very many definitions that we use when we try to operationalize health in the various measures that we're using to monitor the health as a nation.

On one end of the continuum, we have the very traditional, medically-based objective definitions of health that really focus on pathologies, where this is something wrong or different about the way the body structure functions. So that is a very medical model, but it is a concept of health that really does resonate with people.

On the other end of the spectrum, we have the social concept of health. This is different than social determinants of health, which we also talk about a lot in terms of Healthy People. This is where health itself is considered a social concept. And here we're really talking about health as the impact of those pathologies, the impact of the body structure and function on a person's ability to participate in society.

When you get this definition of health here, you're getting into concepts similar to health-related quality of life and well-being. But it is a social concept. It is not so much a medical concept. Both are relevant. Both are important. We talk about both all the time. Unfortunately, we talk about them using the same word, and that tends to lead to a lot of confusion.

Next slide.

First, I want to talk a little bit about some of the measures of health that we've used. There's a set of objective measures that we rely on, and these tend to relate to the medically defined definition of health: lab tests, radiology test, exams, performance measures, medical records. They're considered objective measures but objective measures of the pathology or the body function and structure.

Next slide.

There are also a set of subjective measures that we use. Many of these tend to be summary measures of health. The most commonly use of this is self-reported health status. Now, oddly enough, this is also used as a proxy for an objective measure, so it has two functions, but it is primarily a subjective measure of health.

There are also multiple composite measures. Unfortunately, they have similar names. They all have different components, but they're all trying to get an overall subjective measure of health that encompasses many factors in health. Some of them are using more of the medical model; some of them use more of the social model.

There is another set of measures which relate more to functioning and disability. This can be functioning what we call within the skin, which is without any accommodation. This is your ability

to do things in core functional domains such as walking, very similar to those ACS measures that were discussed. There are also measures that deal with how your ability to do the basic functions interact with the environment and what the impact of accommodations are. So there are a variety of measures that are commonly used as we try to describe health.

Next slide.

The topic of this webinar is disability, and there are a lot of parallels in the complexity of defining disability as there are in defining health, and this has also been mentioned already. There is a definition of disability that's very close to the medical definition of health where you're looking at pathologies in the body. Often this is referred to as impairment, so there will be a missing limb or an inability of the eye to see.

There are a set of definitions of disability that's focus on the actual functioning, but in the core domains without assistance. So you have a lot of questions on the Health Interview Survey like do you have difficulty walking without the use of any assistance. And then there are definitions that look at restrictions in participation; again, very similar to the social concept of health. And this incorporates accommodations, including environmental barriers and facilitators where that outcome is the effect of your pathologies on your ability to participate.

Next slide.

So what are the challenges for us as we try to get some overarching measures for Healthy People or for any other monitoring function? We have a lot of measurement challenges. We have a lot of interpretation challenges. These measures tell us different things, and we have to be very careful in how we incorporate that information into our policy development. Very different kinds of policies would be directed to different kinds of interventions.

Next slide.

Actually, Dr. DeSalvo did a little bit of this early on by looking at the history of Healthy People in terms of some of these measures, and I want to briefly kind of go back through that.

In the early days, life was a lot more simple in 1990. We had five indicators, specific targets. There was a goal for each one. They were tied to different stages of life. Four of them dealt with mortality, clearly one of the objective measures of health. But the fifth was very different. For the 65 and over population, the indicator was talking about preserving independence and using activities of daily living. And here you're moving into this kind of functional approach and also dealing with social participation.

Next slide.

Moving forward, in 2000, there are three guiding goals, the first of which is to increase the span of healthy life, the idea of what is a healthy life coming in here. So it's three measures of that: life expectancy, being in fair or poor health, and a healthy life expectancy. Healthy life expectancies are measures that combine mortality and morbidity measures, so you can look at both together. And a new measure was created for Healthy People 2000, which was a combination of self-rated health and activity limitations; again, picking up on a more subjective measure of the more traditional definition of health but also the social aspects of health.

Next slide.

In 2010, two goals but still the increase in quality and years of healthy life. But where these were combined in the previous decade, now we're separating them out again: expected years in good or better health; expected years free of activity limitations; and expected years free of selected chronic diseases; again, a mixture of the different definitions of health.

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Moving forward in 2020, there were some ideas of expanding on these basic measures. Keep the original three, but add new measures, new healthy life expectancies based on mental health, looking at more measures that are based on behaviors and determinants. While that was attractive because it gives you a better feel for the totality of the topic, it also has a big detriment in that it has lots of measures. And while we're trying to get an overall summary, we wind up with lots of indicators that don't move in the same way, and it's very hard to put them together.

Next slide.

So what do we do going forward for Healthy People 2020? Well, we see a focus on functioning as the key definition of health for policy development and evaluation, and there are several reasons for focusing on functioning in this way. Basic functioning and participation in society is a critical aspect of health both for the individual and society. When we do a lot of cognitive interviewing and asking people what they think health is, very often you get this response of, "Well, what's really important to me is that I can do what I want to do. I can play with my children. I can go to work. I can participate in various activities."

Functioning can also be seen as the outcome of everything else that is under the rubric of health. It is affected by determinants and risk factors, by the translation of those into disease states, by the use of health care to ameliorate those disease states, and by the impact of any environmental barriers or facilitators on that ability to function. And of course, there is a long history of a focus on this kind of measure in Healthy People, so it is kind of a continuation of things that really started in the first Healthy People.

Next slide.

I think from a policy point of view, focusing on functioning has a lot of advantages because there are a lot of ways you can intervene to improve functioning, and it impacts all of the different areas of health. You can prevent the original pathology, and that down the line will prevent any limitation in participation.

You can try to cure the pathology. But if you can't do either of those things, you can reduce the impact of the pathology either through rehabilitation or assistive devices at the person level or by modifying the environment. And our policy activities could involve all of those things, which if successful would be shown as an increase in participation and lessening the effect of any kind of functional limitation on participation.

Next slide.

So if our policy objective is to minimize participation restrictions, which I think it is, then we would want to measure the level of participation and monitor changes in that participation. We'd want to measure the level of basic functioning. And by there, I'm talking about functional abilities within the skin and with accommodation in core activities. And we'd like to relate those measures to the program and policy interventions that we hope are resulting from the whole Healthy People process, the whole idea. These are objectives to figure out how we're going to get there, and we've heard a lot of that figuring out how we're going to get there already in this webinar.

Next slide.

So the plan we put forward for the foundational measures is to focus on a small set of key measures so that we have something that's manageable to use a hierarchical framework where we have two tiers that form an hierarchy, but there's also an hierarchy within the tier, where the most comprehensive and top of the pyramid is the expected years free of activity limitations. This is our participation measure. This is our ultimate goal. This is what we want to increase. And this again is a healthy life expectancy, so it includes the mortality and the activity limitations.

Then we go down to two measures of disability, and here we're defining disability in terms of functioning and core domains without accommodations. This is what feeds into that participation if there is no kind of accommodation made at the societal level. One is a more severe, and one is a milder level of functioning limitation. Then to go back to some of the more traditional measures, expected years in good or better health.

And while people really like these kinds of measures that combine mortality and morbidity, after you show any healthy life expectancy and you show a trend in it, the first question you get asked is, "Did that change because life expectancy changed or the health measure changed?"

Next slide.

So as the tier 2, we suggest showing the components of that, which would be life expectancy and then the percent of the population so that you have an idea about why that overall measure is moving.

Next slide.

So what do we do moving forward beyond 2020? Clearly, there's room to improve our measures of functioning disability and participation. We know that self-reported health, while it's supposed to be getting at more of the traditional health measures, really often picks up some of the social measures. So it's not a pure measure. We know that the activity limitation question is a very difficult one to do, that is to get at that participation. We've used the measure that is being used now for many years in HIS. We'd like to improve that. It probably takes more than one or two questions, but it's important to get limitations in all aspects of life, not just work, which is the one that we actually do best at.

There are a lot of international efforts going on at this point that NCHS has been involved in to try to improve these. I've listed a few here on this slide. And I think it's important to link these efforts in an international context because of the vast amount of work that's going on now around the Sustainable Development Goals. I don't know how much that has come up in these, but there is a great push in the development agenda, and not only in the developing world, but also in the

developed world that all development should be among all people and that no one should be left behind, and also the U.N. Convention on the right for persons with disability, which also focuses on whole participation and inclusion.

So I think by doing this, we fit very well into these international efforts. Thank you and I will hand it back to Dr. Wright.

**DR. WRIGHT:** Thank you, Dr. Madans.

At this point, we'd like to turn the webinar over to Dr. Meg Traci. Dr. Traci is an associate research professor at Montana Disability and Health Program in Missoula, Montana. Dr. Traci?

### **Presentation - Meg Traci**

**DR. TRACI:** Thank you. It is my privilege to represent the 23 years of participatory work on the Living Well with a Disability program and how it is helping to achieve progress in the Healthy People 2020 goals and objectives. I'd like to recognize my co-authors, Craig Ravesloot; Tom Seekins; Glen White; Tracy Boehm; and Naomi Kimbell, and begin our presentation with a brief overview of the program's history.

Next slide.

This history began in 1987 with CDC funding that supported targeted secondary conditions surveillance with people with physical disabilities. Resulting data informed the first edition and pilot of a Living Well with a Disability curriculum and its randomized controlled trial conducted with Centers for Independent Living in 1999.

In 2001 and '05, Living Well was adopted by the national networks of CDC disability and health state programs and ADRCs, and this work was supported through funding sources like Medicaid waiver programs and L.A. Care. Living Well has been translated into Spanish and Korean and also into the Working Well with a Disability program for vocational rehabilitation clients working toward employment goals. Our most recent publication and a special issue of MMWR focused on health disparities summarizes this history more completely.

Next slide.

This U.S. map shows states where research and training center staff have trained Living Well and Working Well with disability facilitators. The 31 states colored blue have both Living Well and Working Well facilitators. The five orange states have only Living Well facilitators. And Nevada, shown here in green, has only a Working Well facilitator at this point. The hash marks on these states show the 19 states that have a CDC Disability and Health program.

Next slide.

As a brief summary of the map, I'll point out that in the last 21 years, research and training center staff have trained 1,181 Living Well with a Disability facilitators in 46 states, who have served more than 9,448 adults with disabilities. Since 2002, 753 of these facilitators were in current or previously funded CDC disability- and health-funded states, and these facilitators have helped to reach more than 6,000 participants whose symptom-free days are estimated at having increased by

71,685 days. And since 2002, research and training center staff have trained 238 working well with disability facilitators in 30 states, who have served more than 1900 adults with disabilities.

Next slide.

So we heard a bit about how we define disability. Here, we've been thinking of disability from the viewpoint of the International Classification of Functioning, Disability, and Health and describing disability as a continuum of function and disability. In this model, disability is not considered an illness. Unlike previous models of disability, the ICF framework considers not only bodily function but also the disabling characteristics of social, cultural, and environmental contexts.

Disability is seen as a dynamic interaction between a person and these contexts. In environments that are inclusive, such as those that include accessible built environments or social structures that support participation for all people, a person with a functional limitation may not experience that limitation as a disability.

Next slide.

In 1999, John Hough defined secondary conditions as those physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible by virtue of an underlying condition, including adverse outcomes in health, wellness, participation, and quality of life. Secondary conditions are associated with poorer overall health and less access to adequate health care. They include issues such as pain, fatigue, and mental health issues, including depression. And importantly, they can be prevented by healthy lifestyle changes like smoking cessation.

Next slide.

So what are the Living Well and Working Well with a Disability program? Living Well and Working Well are goal-oriented, health promotion programs for people with disabilities. Living Well focuses on developing a healthy and balanced lifestyle to meet quality-of-life goals, and Working Well focuses on developing healthy habits that support employment goals. Each program was developed in collaboration with consumers to ensure their relevance to actual health needs, and the independent living philosophy is central to both curricula.

On this slide, there's a photo of a young woman wheeling down a bricked pathway through a garden of roses. And she says that "Working toward my goals is hard, but I feel so much better when I do it."

Next slide.

How does Living Well with a Disability work? Well, Living Well is a 10-week workshop for groups of 8 to 10 people. Sessions are 2 hours long, they meet once a week, and are led by peer facilitators. Peer facilitators have been through the program and can offer support and mentorship to participants. Facilitators guide participants using a self-help workbook, which is pictured here on this slide.

Next slide.

The Living Well program begins by developing basic goal-setting skills. Each chapter in the workbook builds on the next. As participants progress through the workshop, they get to test their skills within a supported peer community, and the building blocks with healthy communication and healthy reactions to stressful situations are learned early to support additional skills.

On this slide, we see a progression through the first half of the curriculum from goal setting, and here I want to emphasize individuals set meaningful life goals like employment, a change in housing, and more friendships. And through the curriculum, they begin to do problem solving to reach that goal. They frame that goal within healthy attributions using healthy reactions, beating the blues, and healthy communication.

Next slide.

The Living Well workshop provides accurate information about health lifestyle habits, including exercise and nutrition. The program helps participants build the skills to find information for themselves and advocate for their needs. The workshops are interactive, and participants have the chance to ask questions and share ideas for maintaining lifestyle changes.

This next slide shows the second half of the curricula, where we proceed from problem solving and healthy attributions into information seeking, physical activity, nutrition, advocacy, and maintenance. So physical activity and nutrition are introduced as a means to reaching those meaningful life goals.

Next slide.

We've summarized here for today some of the benefits of Living Well with a Disability as summarized in the research in the MMWR report cited here on this slide. Some of the personal benefits of Living Well include compared to pre-workshop measures, following the workshop participants, and report of fewer symptom days across physical and mental health symptoms. They showed reduction in activity limitation due to secondary conditions, and they showed improvements in health behaviors and improved life satisfaction. Here on this slide, we see a gentleman biking, and he says, "Taking the Living Well class developed my awareness of ways to better my life."

Next slide.

From a third-party payer perspective compared to 2-month retrospective recall of healthcare utilization, which included outpatient visits, emergency room visits, outpatient surgeries, and inpatient hospital days, and before and after the workshop and converted visits to healthcare costs using 1998 Medicare reimbursement rates, we showed that program outcomes had a \$3,227 savings per person. Study-wide, where we had 188 participants, we showed a \$494,628 saving over six months.

By 2010, using those figures, we estimate that Living Well with a Disability, as implemented by the 279 community-based agencies and 46 states to approximately 8,900 persons with disabilities, that on the basis of those 6-month cost savings observed in the field trial, these community applications are estimated to have saved as much as \$28.8 million, which would have been incurred since February of 1995 by healthcare payers without program implementation.

On this slide, we see Darren Monson, a Living Well with a Disability program facilitator. He says, "The 10-week program allows individuals with disabilities to create a healthy lifestyle plan unique to their desires and strengths, to overcome every day and ongoing challenges, and to reach meaningful life goals."

Next slide.

When implementing the program, we start with facilitator training. Peer facilitators are trained in in-person or in online classroom settings. The program again is delivered through local service providers such as Centers for Independent Living. And finally, to build capacity, we work with our community stakeholders to support program implementation through consumer referrals, funding support, and help in providing facilities and coordination services.

Next slide.

In Montana, we've been working very closely with our partners in the Chronic Disease Prevention and Health Promotion Bureau on a communication campaign called See Public Health Differently. The cover of the communication plan is shown on this slide, and I've included a link. So if you're interested, you can download it. But importantly, See Public Health Differently is a communication plan of the Department of Public Health and Human Services here in Montana that leverages partners statewide to promote health and wellness programs to Montanans.

Living Well with a Disability and Working Well with a Disability are included in this plan with other programs such as the Diabetes Prevention and Self Management Education programs, the Arthritis programs, and the Quit Line. The traditional partners across the state share through this plan and the Healthy People 2020 DH-8 objective with CILs and other disability organizations. We're able to coordinate, through cost-cutting strategies, ways to increase inclusion of people with disabilities in all of these available local health and wellness programs.

We are tracking the participation rates of Montanans both with and without disabilities in these programs, and 11.5 percent of our Montana Breast and Cervical Cancer Screening program participants reported having a disability; 29 percent of participants through the Cardiovascular Disease/Diabetes Prevention program reported a disability; 41.2 percent of the Tobacco Quit Line participants in Montana reported a disability; and 100 percent of those participating in Living and Working Well reported a disability.

Next slide.

This figure shows our current efforts to place Living Well with a Disability into the broader work of health communities through several projects. As we work with our partners to integrate Living Well into this work, we use familiar stages of change to educate our partners on how Living Well is the same and how it is different from other programs. We also are able to impart our shared vision with CILs of how Living Well extends the work of Centers for Independent Living to include healthy communities' work and build the capacity of individuals to engage in this work.

This figure shows how Living Well leverages attributes of our community and of peer support, such as Centers for Independent Living peer support, that affect how people think about their health and how they are motivated to improve it. Living Well supports individuals who are pre-contemplative about the potential of improved health and move them through contemplation to goal setting

through preparation and action towards meaningful life goals. Healthy lifestyle changes are a part of this action, and subsequently, advocacy for healthy and inclusive communities is part of sustaining these changes.

Next slide.

This slide briefly summarizes our current project that's funded by NIDILRR, entitled the Healthy Community Living Project. You heard that we're working with 8 states in 9 communities on these projects to develop and expand the Living Well with a Disability program.

We're developing and evaluating two online programs that blend face-to-face and online learning using traditional video and social Facebook media. The Community Living Skills program is using self-determination theory, as defined by Deci & Ryan in 2000, to help people prepare for health self-management. And the Living Well in the Community program is adapting the Living Well with a Disability course content to an online blended learning format. And again, we're working with 12 staff from 8 CILs in the U.S. through an iterative participatory curriculum development process for program development.

Next slide.

If you want more information about Living and Working Well with a Disability, I've provided a website on this slide and other research reports and publications related to these programs; and our work is at the Research and Training Center on Disability in Rural Communities website, also listed on this slide.

Next slide.

And again, I just want to acknowledge that this has been a participatory two decades of work and that the Independent Living Centers and their consumers, as well as our partners at CDC and NIDILRR, and other RTCs, and the Department of Public Health here in Montana have been essential to that work. Thank you.

**DR. WRIGHT:** And thank you, Dr. Traci, for sharing your work. Thanks to all our speakers. These presentations have been outstanding. Thank you for your work.

At this point, I'd like to turn the meeting over to our session moderator, Carter Blakey, who is Deputy Director of the Office of Disease Prevention and Health Promotion in the Office of the Assistant Secretary for Health. Carter?

### **Roundtable Discussion**

**MS. BLAKEY:** Great. Thank you, Dr. Wright.

We've already received several questions over the platform. But before we begin, I'd like to alert you all that you will have the opportunity to complete a survey about this webinar during the discussion. Your opinions matter to us and help us improve the quality of our webinars, so please do complete it. I'd also like to let you know that a full transcript will be emailed to all the attendees along with a link to the slides. So we do hope that you look forward to receiving that additional information.

So, I'd like to start off with a question to Meg Traci having to do with your Montana program. On the See Public Health Differently slide, your data seem to suggest that other chronic disease prevention programs are monitoring their programs for the inclusion of people with disabilities. Can you say a little bit more about how this and other efforts have happened?

**DR. TRACI:** Sure. So this happened through the state-funded Disability and Health program. We're very integrative with our Chronic Disease Prevention and Health Promotion Bureau, and one of our key strategies for reaching DH-8 is to improve the accessibility and inclusionary aspects of the different health and wellness programs that are available state-wide.

And so in the chronic disease plan in the state, we have the objective of including those ACS or HHS standard disability demographic items in our participation-monitoring tool across all those programs. So we're beginning to get those data and starting to publish them. We're also working very closely with all of the facilitators and building their capacity to better include people with disabilities in the variety of programs state-wide. We also look at the facilities where the programs are offered and really try and support the accessibility of those facilities.

You heard similar efforts to what South Carolina was shown to do with medical facilities.

**MS. BLAKEY:** Great. Thank you so much.

John Tschida, I have a question for you. What evidence is there showing that the Living Well with a Disability and the HealthMatters programs are effective?

**MR. TSCHIDA:** Great question. I think what we just heard from our colleagues at the University of Montana touched on a little bit of that. I would defer to Meg Traci to speak more about that.

I think the HealthMatters program, I'd be happy to connect the individual folks with our project officer, Hugh Berry, who is our staff member who has overseen and been the project officer through the development of this HealthMatters program. I would say we are not at a point with HealthMatters to say that it is evidence-based, but we do have indications that it is in between that space, between promising practice and evidence-based, to show that it is showing some effective outcomes; and, again, would be happy to follow up with the individual question or to link them to that information directly.

**MS. BLAKEY:** Thank you very much.

Dr. Cernich, a question for you. How are research studies that develop measurement instruments vital to moving forward the Healthy People objectives?

**DR. CERNICH:** That's a great question, and some of the data that was presented earlier by Director Rothwell actually speaks to this. NH led the development of the PROMIS measures in conjunction with some of the other agencies. In that large initiative to develop measures such as PROMIS and the quality-of-life measures, and other toolbox measures, allows for widespread adoption and norms for the U.S. population that can then be used in subsequent surveys to track the health of the nation.

So as we approach that from a public health perspective, it's really vital to do that, being representative of a number of different populations, different socioeconomic statuses, and to also

ensure that people with disabilities are included in those approaches so that they can be included in efforts like Healthy People.

**MS. BLAKEY:** Thank you.

We have a question for the National Center for Health Statistics, for Director Rothwell. Why do the health-related quality-of-life and well-being objectives have baseline data only? And when will the data update be available from the PROMIS measures?

**DR. ROTHWELL:** I was afraid somebody would ask that question. The baseline data were collected by the National Health Interview Survey supplement, which was funded by the National Cancer Institute at NIH. Now, with the Health Interview Survey, supplemental questions are sponsored by external agencies, not by NCHS, and these eight questions have not been included in NHIS since the 2010 example. Further data updates will depend upon future sponsorship by such agencies for questions for NHIS or perhaps funding this in another national survey other than NHIS.

**MS. BLAKEY:** Thank you.

We can move back to CDC Atlanta. Dr. Peacock, is there any evidence that the inclusion of full participation of people with disabilities in public health activities leads to better health outcomes?

**DR. PEACOCK:** Yes. Across publications and disseminated findings, we see evidence base that exists on the scale of emerging or promising. And it's fairly solid though not necessarily prioritized evidence of disability health disparities and that some things should be done, as well as some evidence of what needs to be done in small groups; but there is far less evidence about how to implement effective programs in large and diverse populations. And I think the disparities in health indicators between people with and without disabilities, that have been highlighted today, provide some powerful argument that more work needs to be done in this area.

**MS. BLAKEY:** Thank you. Then we'll move right back to the National Center for Health Statistics, and Jennifer Madans. Is NCHS currently doing any work to develop international capacity in the area of statistics?

**DR. MADANS:** One of the international activities I mentioned on the slide is a group that operates under the U.N.'s statistical commission. It's called the Washington Group on Disability Statistics. That group has been extremely active in developing the international standards for disability data collections, and those questions have also been used on the HIS.

Because of the push towards the Sustainable Development Goals and the need to disaggregate data by disability status exactly as it's done in Healthy People, the Washington Group was lucky to get a grant from the Australian Department of Finance and Trade to support technical assistance and regional workshops to increase the capacity of countries to incorporate these questions onto their censuses and surveys. And that work is going on now and will kind of peak around the 2020 rounds of censuses.

**MS. BLAKEY:** And then to follow on to that, how does the U.S. Healthy People initiative align with these international efforts?

**DR. MADANS:** I travel a lot because of this international work, and I get questions about Healthy People often. There is a lot of interest in how we have approached this. Many countries also have monitoring functions. I will say that when they see the number of indicators we have, they kind of are quite amazed since most of theirs are under 20.

But I think the focus in Healthy People, the longstanding focus on healthy life, quality of life, participation, those kinds of outcomes, is something that is very relevant to many countries right now. They tend to be doing them in different ways. The European countries have a much more coordinated way, and they have included the U.S. in that, and their focus is on developing better measures. But the group that has been working on that has come forward with a proposal that there should be this overall -- some kind of participation measure, and then supporting that, some of the functioning measures that we talked about.

**MS. BLAKEY:** Great, thank you.

I have a question for Dr. Peacock. What are the CDC and Healthy People 2020 doing to work toward the social model of disability approach; in other words, treating people with disabilities as a population rather than as a public health problem?

**DR. PEACOCK:** So I think in order -- some of the things that we heard about today from our colleague in Montana, with the support of the Living Well with a Disability program, is an example of the way CDC is able to support this approach through our state facility and health programs and national partners. Another example, which I had shared before, was the healthy community's project to reach people with disabilities, which both of these are aligning with the objective to reduce barriers to local health and wellness programs and also increase community participation.

**MS. BLAKEY:** Thank you.

Meg Traci, we have another question for you. It seems that people with disabilities have been involved in the methods to design the program from the beginning. How does this relate to the new Patient-Centered Outcomes Research Institute initiatives that have a similar orientation to your program in Montana?

**DR. TRACI:** Thanks for that question. This just gives me a chance to highlight, I think, the commitment that has come throughout decades now of research in the areas of rehabilitation and disability that are stemmed within the "Nothing About Us Without Us" philosophy. I think NIDILRR -- former name NIDRR -- they had a whole approach that we called "constituency-oriented research development" that emerged and was a part of CBPR and PAR.

I think that as we move towards this patient-centered outcome research, and really wanting the healthcare service to realize outcomes in the community, and we work to strengthen the clinic and community linkages to achieve those outcomes as defined by the patient -- "I'm here to get this healthcare for these reasons, as I've defined them, and you're successful if I say you are" -- that is a very resonant approach with disability. And I really think that the work that we've done over the years to establish that methodology and that approach is very relevant to benefitting patient-centered outcome research across all populations.

So that's my perspective on that question.

**MS. BLAKEY:** Great. Thank you.

We're fortunate to have additional people besides our presenters here today to answer questions. Lisa Sinclair, who has traveled up to Washington, D.C. from Atlanta, is at the table. And here's a question that, Lisa, I think you can answer.

Outside of granting dollars to primary care facilities to increase physical accessibility, what is the role of the state health department?

**MS. SINCLAIR:** Thank you for that question. One of the roles of state health departments through our funding stream is to go out and help facilities understand and measure where their improvements might take place. We have several instruments that are standardized that can take assessments of those facilities. The state health departments are there to support this effort and to also make sure that they do outreach throughout, across the states.

**MS. BLAKEY:** Great. Thank you.

Dr. Cernich, a question has come in that I think you should be able to answer. What data is being collected regarding persons with disabilities being denied to be on the transplant list because of their disability or because of one disability?

**DR. CERNICH:** I'm not sure that this data specifically speaks to that, but I know that there are data from the Center for Medicare and Medicaid Services related to organ transplant within their program, and there is a website for this on the Center for Medicare and Medicaid Services, where you can actually request data. So it may be that you can look to them since they do run many of the transplant programs.

There are also data from specific foundations, for example, the National Kidney Foundation, that may be applicable to that question. I don't have a specific answer with respect to rates of denial, but I do know that there are some data out there related to the outcomes of organ transplant processes.

**MS. BLAKEY:** Great. Thank you.

Going back to the National Center for Health Statistics, Charlie Rothwell, what are the specific barriers to primary care for adults with disabilities?

**DR. ROTHWELL:** Some examples of those barriers would include a person with disability who couldn't get through on a telephone; or couldn't get an appointment soon enough; or once a person got there, he or she had to wait for a long time to see their doctor; or the office wasn't open when the patient could finally get there; or the person didn't have transportation to get there.

There are just a variety of things that come up when you have a disability that we don't normally think about, those of us who can get around easily, that really can impact a patient getting appropriate care.

**MS. BLAKEY:** Great. Thank you. We have time for a couple more questions.

Dr. Peacock, in what activities do the state disability and health programs engage with you in your efforts?

**DR. PEACOCK:** Sure. I think we've heard about a few already, so I'll just name a couple others that we work on. Increasing awareness of health-related disability policy initiatives through different kinds of disability policy summits. There are health promotion opportunities. There are increasing health promotion opportunities for people with disabilities by supporting training that maximizes the health of people with disabilities and implements health awareness education campaigns. And a third might be improving access to health care for people with disabilities by looking at accessibility in healthcare facilities, and then educating healthcare professionals through continued education. So really, the disability and health programs do approach this work in a number of different ways, and those are just a few of those.

**MS. BLAKEY:** Great. Thank you.

Our final question that came in from one of our participants I'll direct back to Lisa Sinclair. Is there a collection and analysis of data on incidence of domestic and intimate partner violence against persons with disability?

**MS. SINCLAIR:** Thank you for the question. I think so. One of the recent instruments to include some disability identifiers, specifically the six ACS questions, is the National Survey on Violence. I have the name of the survey here. I know the data are probably available, but I'm just not sure if they've been analyzed yet. That's really my question back for us. But I'm recalling that before Vincent Campbell retired recently, he sent me a link to a report that's recently been out, and I'm just not sure what's in that report. But I would say we should go and take a look at that.

**DR. WRIGHT:** Thank you, Carter, for moderating that session, and thanks to all of our presenters today for their leadership and for sharing their work.

These webinars bring together rich data and diverse partners from across HHS. Certainly, this could not be done without a group of dedicated public health professionals. Thank you for your commitment to Healthy People. And finally, let me say we invite all of you to stay connected to Healthy People through the web and on social media. Thank you again for joining us once again.

(Whereupon, the webinar was concluded.)