Transcript for "Be Active, Eat Healthy, Have Fun: Promoting the health of people with intellectual and developmental disabilities," a presentation by Sara Rainer and Dr. Kimberly Phillips for the New Hampshire Disability & Public Health Project.

(Sara)

Hello and thank you for tuning in today!

My name is Sara Rainer and I'm here with my co-presenter, Kimberly Phillips.

Today we'll be sharing our presentation, *Be Active, Eat Healthy, Have Fun: Promoting the health of people with intellectual and developmental disabilities*.

(Kim)

This presentation was created as part of the New Hampshire Disability and Public Health Project, or DPH. DPH is funded by the US Centers for Disease Control and Prevention, and housed at the Institute on Disability at the University of New Hampshire in collaboration with the New Hampshire Division of Public Health Services.

(Sara)

The overarching goal of DPH is to improve the health and quality of life of people with intellectual disabilities and mobility limitations.

Today we are here to share information with you about health disparities, what are they and why are they important to address? We'll talk about barriers to health experienced by people with intellectual and developmental disabilities, and we'll share resources, strategies, and best practices to promote health and wellness.

First we'll hear from Kim Phillips who's here today to talk to you about health disparities.

(Kim)

Thank you, Sara. First let's start with a definition. A health disparity is a difference in health among certain groups or subgroups of the population. Often health disparities are associated with racial or ethnic minorities. For example, we know from our research that American Indian Alaska Natives are more likely to smoke cigarettes than white people. We also know that in New England Native Hawaiian Pacific Islander youth are more likely to abuse alcohol and other substances than their white counterparts.

But people with disabilities are increasingly being recognized as experiencing health disparities. For example, women with mobility limitations are less likely to get mammograms at recommended intervals than women without a mobility limitation. And plenty of research shows that people with intellectual and developmental disabilities also experience health disparities. Understanding health disparities is a crucial first step in being able to address them and work toward greater health equity. To really understand where some kinds of health

disparities come from we first need to think broadly about health and the kinds of things that enable or prevent us from making healthy choices.

This figure shows the social determinants of health. That's what "SDOH" in the center stands for - social determinants of health. It means that people's socio-economic environment can strongly impact their health. Let's consider some examples. In the bottom left corner, the turquoise circle says, "Education." We know from research that lower educational status is associated with poorer health outcomes. Moving up to the orange circle which says, "Economic Stability," people with disabilities are less likely to be employed than people without disabilities. This often means lower income, and like education, economic instability and low income is associated with poorer health and fewer healthy behaviors. Lack of employment can also mean less access to employer provided health insurance and other benefits.

At the top of the figure, the red circle says, "Neighborhood and the Built Environment." How can this impact health? Well, if you have a local farmers market and a Whole Foods down the street chances are you have better access to healthy food choices than a neighborhood with only a gas station mini-mart that may or may not have a Dunkin Donuts or Krispy Kreme attached. Also in this circle is the built environment. Is your local gym accessible? Meaning both the building itself and culturally. If people who attend the gym are open and welcoming to different kinds of people at different levels of fitness, that positively impacts accessibility. Of course the green circle, we see, "Health and Health Care" definitely impact wellness, and Sara will talk more about that in a little while.

Finally in purple, "Social and Community Context." Thinking about an individual's social and community context is especially interesting for people with intellectual and developmental disabilities and other kinds of disabilities that involve their dependence on others in order to maximize functioning. In such a case, we are looking not just at one individual and influencing the health of that one individual but in fact the whole constellation of people who support that person as well. My purpose here is to introduce the idea that addressing health disparities needs to happen on many fronts, and again, Sara will talk more about that in a bit.

Why is it important to address health disparities? Because people with intellectual and developmental disabilities can be healthy and deserve to be healthy. Good health means a longer life and a better quality of life, maximizing independence, community participation, and overall well-being.

Researcher's measure good health using several types of indicators, including healthcare access; health behaviors, like smoking, eating choices, and physical activity; and health outcomes, like disease or other biological indicators.

Let's look at some data examples now

Starting with healthcare access – people with a cognitive disability are almost three times more likely to delay care than people without a cognitive disability. 30% of people with a cognitive

disability indicate that they had to delay or forgo needed medical care due to cost in the past 12 months, compared to 11% of people without a cognitive disability. These data come from the Behavioral Risk Factor Surveillance System, which is a national telephone survey administered by the Centers for Disease Control and Prevention.

Another example from healthcare access: 48% of people with a cognitive disability were not able to see a dentist or receive a tooth cleaning in the last 12 months, compared to 30% with no cognitive disability.

Here are some examples of health disparities in health behaviors. 48% of people with a cognitive disability say that they do not eat fruit at least once a day, compared to 40% of people with no cognitive disability. Similarly, 30% of people with a cognitive disability say that they do not eat any vegetables at least once a day, compared to 21% with no disability. Regarding physical activity, 66% of individuals with a cognitive disability say that they are active less than 30 minutes a day, compared to 56% of people without a cognitive disability.

This slide shows a different data source. National Core Indicators is collected in 46 states in the US from people who receive some type of developmental disability services. What we see here is that only 22% of people who receive DD services say that they engage in regular physical activity at least 30 minutes a day at least three times a week.

Turning to health outcomes and returning to the Behavioral Risk Factor Surveillance System, we see that 37% of individuals with a cognitive disability are obese, compared to 28% of people with no cognitive disability. Comparing that to National Core Indicators, we see that 33% of people who receive DD services are obese.

The health disparities that I've just discussed with you result in part from barriers that many people with intellectual and developmental disabilities face to health and healthy lifestyles. To help provide a better understanding of health disparities, Sara Rainer will next discuss some common barriers to accessing health care, health information, and healthy behaviors.

(Sara)

Many people with intellectual and developmental disabilities experience barriers to healthcare. Insurance constraints may limit an individual's ability to access health care. Individuals may not have health insurance or may not have sufficient coverage to meet their medical needs. Even those who have insurance coverage may not know what is covered under their plan, or may have coverage that limits the providers they can see, affecting the care that they receive. For example, most state Medicaid programs do not cover dental care for adults.

Another challenge can be finding a health care provider willing to work with a person with intellectual and developmental disabilities. Attitudes such as discrimination, assumption, stereotype, impatience, and inaccessible communication pose barriers to providing appropriate care.

Lack of knowledge among providers about intellectual and developmental disabilities contributes to this barrier. Providers may be unfamiliar or uncomfortable treating people with IDD, and may attribute problems that the individual is experiencing to the disability instead of as a co-occurring concern. Providers are also less likely to recommend preventive action and health promotion for people with IDD such as prescribing physical activity to an individual who is overweight or obese.

Some people with intellectual and developmental disabilities experience barriers to accessing health information. They may not know or understand the benefits of healthy eating and physical activity. If something doesn't taste good or an activity causes muscle pain, why would one automatically think that it's good for you? Take oral health as one example. Brushing your teeth may seem like nothing more than a daily chore - something you have to do when you wake up and before you go to bed – because that's how it is. But, when you consider that brushing your teeth improves your breath so people enjoy talking to you more, it brightens your smiles so you look better, and it helps prevent serious illnesses, not just in your mouth but in your brain and other parts of your body, suddenly brushing your teeth might seem more important.

So, knowledge and awareness actually provides motivation and opens the door for some self-determination to take over.

Part of the reason that people may lack knowledge and awareness about the importance of health and healthy living is that people with IDD are likely to be missed by mainstream health education efforts. A lot of messaging that we receive about health, wellness, nutrition, and exercise are not necessarily reaching people with IDD. For example, community health promotion often requires reading skills that may be beyond the skill level of many people in IDD. In addition, a growing number of health promotion programs use the internet as a means of reaching people. Some people with IDD may not have access to a computer or may not have the skills needed to pick out relevant information and synthesize it into their own lives. Social media sites are a new and promising mode of disseminating health messaging. However, some people with IDD are unlikely to access and benefit from this type of health promotion.

In addition to lack of knowledge and awareness, people with IDD may experience other barriers to engaging in healthy behaviors. Transportation may limit a person's options and independence as it is not always available and it can be expensive. Insufficient financial resources make it difficult for some people with IDD to get around and it can make it challenging to make healthy choices that have added expenses, such as a gym membership or the cost of fresh and healthy produce. Inadequate community and personal support make it difficult for some individuals to take the lead in making healthy choices. Often times, individuals with IDD are dependent on the choices of others, what we like to call the "extended care network," such as family members or personal care attendants. This dependence on others makes it much more challenging for a person to decide, on their own, that they want to be more active and eat healthy.

Before we leave this section on barriers we want to share this story about Steven. This comes from a publication from the American Association on Intellectual and Developmental Disabilities. Steven was initially reluctant to join a health promotion program at the organization where he received services. He wrote a poem, "The Way I Used to Be," about his experiences trying to be active and eat healthy.

(Kim)

The way I used to be, by Stephen Love:
“I used to be as big as a tree
Just like my whole family.
They would fill themselves with cakes and pies
and never want to exercise.
When I wanted to lose weight
they called me names and filled me with hate.
'You're not going to lose weight you idiot,
you're going to be fat like us you twit.'
But that drove me to work hard
I pushed myself from the start.
I worked hard fast and quick
I was losing weight by the look of it.
Now they look at me with pain
At the falsehood of what they say.
You can do what you envision
You just need will and good motivation.

(Sara)

Now, we are going to share some resources and strategies that are available to promote health and wellness. We're going to focus on two approaches to reduce health disparities and remove barriers to health - promote health & know your resources.

To promote health, is important to impact multiple levels of influence. We are going to provide examples of strategies and resources that address each level within this framework, which is known as the Social Ecological Model. Each circle represents a level of influence and a key point for prevention to reduce health risks and increase health promotion opportunities. As we make our way through the peels of the onion we reach the individual who needs knowledge, attitudes, and skills to advocate for their own health.

Our first examples focus on the outer layers, which are more macro-levels of influence. The Centers for Disease Control and Prevention support nineteen State Disability and Health programs, which are highlighted in green on this map. These programs aim to promote and maximize the health of people with intellectual disabilities and mobility limitations. The CDC supports these states to plan, implement, evaluate, and disseminate non-research activities to

promote inclusion and accessibility and reduce health disparities between people with and without disabilities.

The CDC is not alone in their efforts. Here are a few national organizations that support inclusive health initiatives: the American Association on Health and Disability, the American Public Health Association, the American Association on Intellectual and Developmental Disabilities, and the Association of University Centers on disabilities. These are just a few organizations that are involved with policies and actions to promote equal opportunities for people with disabilities.

We also have the potential to influence health behaviors at the organizational level. A great example of an organizational level resource is Commit to Inclusion. The Commit to Inclusion campaign allows organizations and programs that have a focus on nutrition, physical activity, and obesity prevention to sign up as an advocate for inclusion. When they join the campaign, they are provided with guidelines to help build healthy inclusive communities. Their page hosts resources to support programs and organization to take action, from a media toolkit to share inclusive messaging to guidelines that community health programs can use to support disability inclusion. Visit their webpage for action resources and to learn about the activities and undertakings of organizations that have made the commitment to inclusion.

In many cases it is essential that the extended care network, families, friends, and caregivers, have access to the same information, training, and opportunities to improve physical activity and health behaviors that are available to the person with IDD. For example, a woman with IDD whose mother cares for her will have a much easier time eating a nutritious, balanced diet if her mother has a cache of easy to prepare, affordable, and well balanced recipes. Similarly a man who relies on his care provider to drive him to the gym every other day will be more likely to get there regularly and perform his exercise routine if the care provider also has a gym membership, and can work out alongside the individual helping and motivating each other as they go.

One health promotion idea is to model healthy behaviors. Modeling is a tool that some people use really successfully. Even small examples can make a big difference. Modeling healthy behaviors can include choosing healthy foods when eating together, choosing activities that get you moving, and talking about the benefits of these healthy activities.

It's important to use the resources and opportunities that your community has to offer. Check out local farmers markets and community gardens, sign up for a walking club or other community exercise program. As Kim mentioned earlier, not every community has equivalent opportunities. Sometimes we have to get creative and use what we've got. Something as simple as a walk around the neighborhood or setting up a community dance can be beneficial. In communities that are not resource rich, bring people together to bring some ideas of how to get active. Whatever you do, make it fun. The main message is to get healthier, get moving, and be a role model.

As part of the New Hampshire Disability and Public Health Project, we are working with an organization that provides Developmental Services, advising on the adaptation of a physical activity and nutrition program for people with IDD. This is a snapshot of one of the resources we have developed as part of this initiative. This handout talks about the importance of staying hydrated, especially when we're getting active. Our goal is to ensure that the materials are accessible and that the extended care network has inclusive information that they canshare. We have learned a lot as we've worked on the adaptation of this program. We always try to make it positive and we make it about choices. We don't use the word “diet” and we don't talk about cutting any foods. Rather, we talk about adding or substituting. We offer gym memberships for people with IDD participating in the program as well as for the person who is most likely to be taking them to the gym, whether that's a family member or day staff. We have weekly check-ins with the extended care network and we celebrate success. Quarterly celebrations bring together everyone who's involved in the program.

A great resource is the National Center on Health, Physical Activity, and Disability, also known as NCHPAD. NCHPAD is one of the largest sources of information on disability and health. The web-based information center offers a searchable database of articles, video clips, and programs, on the many areas of physical activity, equipment, and exercise guidelines for specific disabilities. There are resources for educators, individuals, caregivers, and fitness professionals.

The individual lies at the heart of the Social Ecological Model. To promote health at this level we strive to distribute inclusive health messaging. We develop, deploy, and test the success of health messages that everyone can use and understand. The goal is to increase knowledge attitudes and skills regarding healthy behaviors among individuals with IDD, while also reaching the extended care network.

A great resource for inclusive health messaging is My Plate. My Plate is the current nutrition guide from the US Department of Agriculture. They provide easily digestible health and nutrition information. We've talked about mainstream messaging missing people with intellectual and developmental disabilities. My Plate has done a very good job designing their resources for a wide audience. My Plate's colorful food guidance symbol helps to illustrate the five major food groups. This resource can be the basis for fun activities that center on healthy eating choices. You can talk about nutritious foods by placing food items you like to eat in each corresponding category, or walk around the grocery store identify where on the plate different foods fit.

My Plate also features resources about increasing physical activity. This is a snapshot of one of their new series, My Plate My Wins, which provides tips to build a more active and healthy lifestyle. My Plate has several online tools that can help you plan and track your physical activity and a lot of fun quizzes and games to test your knowledge about health. We are impressed with the design of their work and definitely suggest that you check them out.

Another example of inclusive health messaging is the Small Steps Campaign. Small Steps health messages were created as part of the Health Matters program, which is a health promotion and advocacy program for people with intellectual and developmental disabilities. The Small Steps campaign sends weekly tips to participants, encouraging individuals to engage in healthy behaviors. This is a great example that shows how small reminders can start to lay the groundwork for meaningful change.

(Kim)

That concludes our presentation. We've discussed health disparities, what they are and why they are important to address, we discussed some of the barriers that people with intellectual and developmental disabilities experience to health and healthy lifestyles, and we shared some resources strategies and best practices to promote health. We hope you found this helpful and we would really like to hear from you.

(Sara)

You can reach us via our website, nhdisabilityhealth.org, where you will also find a link to the evaluation survey for this presentation. You can also find additional information and resources on our webpages, and also find and follow us on Facebook and Twitter, along with the many organizations we noted throughout our presentation. If you haven't already, join the disability community on social media sites to stay up-to-date on strategies to improve health, best practices, resources, news, and more.

References

1. *Healthy People 2020. Social Determinants of Health. Retrieved on April 5, 2017, from https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health.*
2. *Scott HM & Havercamp SM. (2016). Systematic Review of Health Promotion Programs Focused on Behavioral Changes for People With Intellectual Disability. Intellectual and Developmental Disabilities, 54(1), 63-76.*
3. *Heller T & Sorensen A. (2013). Promoting Healthy Aging in Adults With Developmental Disabilities. Developmental Disabilities Research Reviews, 18, 22-30.*
4. *Centers for Disease Control and Prevention. (2013). Social Ecological Model. Retrieved on March 20, 2017, from www.cdc.gov/cancer/crccp/sem.htm.*