

Presidential Address: Promoting Health and Wellness

Susan M. Havercamp, President, 2017–2018

I am honored and humbled to stand before you as the incoming president of the American Association on Intellectual and Developmental Disabilities. I must tell you how much I value the AAIDD community. I feel that AAIDD is my professional home. Over the years of coming to the conference and getting involved in the association, I have come to know admired colleagues and, though I always look forward to the scientific content presented at the meetings, this conference is my favorite time of year because I can reconnect with friends, many of whom I only see here. I encourage you to get involved in this organization. AAIDD offers great opportunities to pursue interest networks and regional connections and leadership roles in the field of intellectual and developmental disability.

I am excited to talk with you today about a topic that is central to the lives of people with disabilities and their families, yet rarely considered in service planning. I believe that health and wellness are critical to quality of life. I was excited to plan this 2017 AAIDD meeting with a focus on promoting health and wellness. I enjoyed so many conversations at this conference about individual and systems change efforts to make it easier for people with developmental disabilities to live healthy lives. I'd like to share a story that resonates with me and the health promotion theme of this conference. This was taken from a Joseph Malins poem circa 1895 but well describes the current dilemma in developmental disabilities (DD) services and society writ large. The poem is called *The Ambulance Down in the Valley*.

'Twas a dangerous cliff, as they freely confessed,
Though to walk near its crest was so pleasant;
But over its terrible edge there had slipped
A duke, a prince, and full many a peasant.
So the people said something would have to be done,
But their projects did not at all tally;
Some said, "Put a fence 'round the edge of the cliff,"
Others, "An ambulance down in the valley."

This poem reminded me of the great debate in American healthcare today. On the one hand, we

should invest more in hospitals and specialists to treat chronic health conditions that are overwhelming the healthcare system such as cardiovascular disease and diabetes. On the other hand, we should fund public health efforts to address the factors that cause the chronic health conditions in the first place.

Before I go any further, let me say a word about the poem's fence analogy. I am **not** talking about limiting choices for people with intellectual and developmental disabilities. The conversations at this meeting explored what prevention efforts should be considered in developmental disability services, not to limit choices but to make sure that for people with developmental disabilities are fully aware of the risks to their health. I am definitely not talking about a wall or even a high fence. I might suggest a low fence like around a flower bed to serve as a warning. So that one must consciously step over the fence to risk one's neck. I would like to talk today about the cliffs for people with DD and the fences we can leverage to promote health and well-being.

Health Risks

Health promotion is the process of enabling people to increase control over, and to improve, their health. It covers a wide range of social and environmental interventions designed to promote health and quality of life by addressing and preventing the root causes of ill health. The following three elements are key to health promotion: health literacy, individual choices, and social and environmental factors. Health literacy has to do with understanding health well enough to make appropriate health decisions. In a perfect world, health literacy improves individual choices such as wearing a seat belt, smoking, diet, and physical activity. Finally, social and environmental factors can have a profound impact on health outcomes. I will discuss the health risks for adults with DD in the areas of health literacy, individual choices, and social and environmental factors.

Health Literacy

What do we know about health promotion among people with developmental disabilities? We know that adults with DD have limited understanding of health risks associated with a sedentary lifestyle, an unhealthy diet, tobacco use, and substance use. We also know that adults with DD have difficulty advocating for themselves in health care settings and have limited knowledge of early detection cancer screening. Lack of health literacy is a predictor of poor health outcomes for people with and without disabilities.

Individual Choice

In terms of individual choices, we know that adults with DD have unhealthy diets that include more sugar, fat, and fried food and less fruit, vegetables, fiber and protein compared to adults without disabilities. You may not be surprised to hear that overall adults with DD are very sedentary; they are 4.5 times more likely to be sedentary than adults without disabilities. Another serious risk to the health and wellbeing of adults with DD is their lack of social support. Adults with DD report feeling isolated and lonely; in fact, the National Core Indicators found that 23% of a representative U.S. sample reported that they did not have a best friend of anyone to talk with about personal things, even when family and staff members were included among confidants. There is a robust relationship between social and emotional support from others and health outcomes including immune function, diabetes, heart disease, arthritis, rate of wound healing, and mental health. Finally, in terms of health care, we know that adults with DD underuse health care, particularly specialty care and preventative care. And we know there are serious concerns about the quality of care provided, especially mental health care for this population.

Let me clarify lest you infer from this discussion of health risks that I advocate for limiting choices or telling people how to live their lives. To me, health promotion is a social justice issue- people with developmental disabilities have a right to know the consequences of their health choices and at the present time they do not. We in the developmental disability service community recognize that adults with DD have rights and responsibilities. They have the right choose what to eat and what to do. They certainly have the

responsibility of living with the consequences of these choices. My point is that they have the right to understand the risks associated with their choices. This understanding is the fence I was alluding to earlier.

Sandy Magaña, Wendy Jones, and Alixe Bonardi spoke eloquently about efforts to achieve health equity for people with intellectual and developmental disabilities. Health equity refers to efforts to ensure that all people have full and equal access to opportunities that enable them to lead healthy lives. Health inequities are differences in health that are avoidable, unfair, and unjust. There is growing recognition that a broad range of social, economic, and environmental factors shape individuals' opportunities and barriers to engage in healthy behaviors.

Social and Environmental Influences (Social Determinants)

One way to understand social determinants is to consider that children born to parents who have not completed high school are more likely to live in an environment that poses barriers to health. Their neighborhoods are more likely to be unsafe, have exposed garbage or litter, and have poor or dilapidated housing, and vandalism. They also are less likely to have sidewalks, parks or playgrounds, recreation centers, or a library. In addition, poor members of racial and ethnic minoritized communities are more likely to live in neighborhoods with concentrated poverty than their poor white counterparts. Education status is a major predictor of health outcomes. Life expectancy is increasing among the most educated Americans but *decreasing* among the least educated. Educated Americans differentially develop a range of skills and traits, including cognitive skills, problem solving, and social skills or soft skills that are critical to health. Another significant contributor to health inequity at lower income levels is psychosocial stress. Stressors include exposure to violence, substandard housing, family turmoil, food insecurity, and racial bias. Children born into poverty experience chronic stress and poor health outcomes. When public policies widen the gap between rich and poor, they may have a negative impact on population health. Finally, to put a fine point on this social determinants discussion, a meta-analysis of nearly 50 studies revealed that social factors, including education, racial segregation, social

supports, and poverty accounted for over **one-third of total deaths** in the United States per year (Galea, Hoggatt, DiMaggio, & Karpati, 2011).

The importance of individual behaviors and social determinants can hardly be overstated. In fact, McGinnis, Williams-Russo, & Knickman (2002) evaluated the impact of different factors on the risk of premature death. They considered four factors: genetics, individual behavior, social determinants, and healthcare. You might expect health outcomes to be largely determined by genetics and health care, but you would be surprised. This study found that genetics did explain about 30% of health outcomes. As there is very little to be done about genetic endowment to improve health and wellbeing, I will focus on the other three factors. The biggest determinant was individual behavior, explaining an impressive 40% of the variance in premature death. Social and environmental factors accounted for an additional 20% of the variance in health. Perhaps the biggest surprise in their findings was that health care only accounted for 10% of the health variance (Figure 1). Keep this distribution in mind when I tell you that, of the trillions of dollars spent on health in the United States, approximately 95% goes to the financing and delivery of healthcare services while only 5% of spending is directed to health promotion. We are preoccupied with the ambulance but I want to talk about programs that can promote health. Health promotion is about building fences to improve health by way of individual behavior and social and environmental factors.

Promoting Health Among People With DD

Adults with DD have rights and responsibilities with respect to their health. For the most part, they choose what to eat and what activities they engage in. They live with the consequences of these choices. One consequence is the rising obesity rate, especially for adults living independently or with few restrictions. Obesity leads to serious health conditions that limit quality of life including heart disease, stroke, type 2 diabetes, and respiratory problems. Adults with DD have a right to understand the risks to their health (health literacy). And to appreciate the connection between how their choices about what to eat today can affect how they feel tomorrow.

Impact of Various Domains on Premature

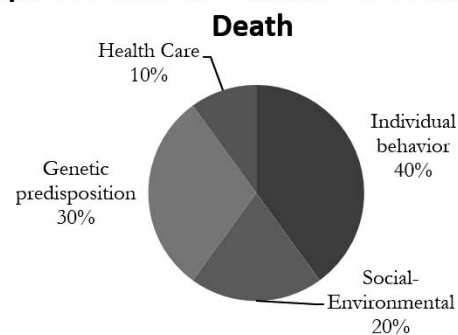


Figure 1. Impact of various domains on premature death. Adapted from McGinnis, Williams-Russo, & Knickman (2002).

Health Promotion Programs

There is an exciting evidence base emerging on health promotion programs designed for adults with DD that improve both health literacy and health choices. Programs have been developed that focus on nutrition and healthy eating, physical activity, stress management, and health communication. These programs are similar in that they include both didactic and hands on activities. They offer opportunities to practice skills such as cooking or exercising and they focus on sustainable behavior change. The other element that many of these programs have in common is that they are offered in small groups of peers with developmental disabilities.

The fact that health promotion programs are often offered in small groups is particularly important for adults with DD. As I mentioned earlier, social and emotional support from others affects key health outcomes including immune function, diabetes, heart disease, arthritis, rate of wound healing, emphysema, and mental health. Yesterday, Tim Shriver emphasized the unrealized value of relationships for people with DD. We know that having a trusted friend or confidant provides an outlet for frustrations and fears, gives assistance and support in hard times, improves self-image, and enhances quality of life. In fact, among adults with DD, having good social networks are associated with being 50% less likely to have mental health problems. Unfortunately, adults with DD report feeling lonely much of the time.

I believe that DD service providers are in a unique position to promote the health of people they serve with DD. One idea would be to include

health behavior goals in Individual Support Plans. I am thinking of goals like “try a new vegetable every week” or “go for a walk every day.” This could generate a conversation among team members about how to provide and encourage healthy choices. Some simple changes could make healthy choices more attractive and easier where people with DD live and work. For example, display pitchers of water flavored with fresh fruit, vegetables, or herbs. Suggest a walk, Frisbee golf, geocaching, dancing, playing catch or anything other than going out to eat again. If DD service providers are mindful about fostering a health promoting culture, adults with DD will benefit.

Direct Support Professionals

For us to improve the health culture of adults with DD, we need the help of direct support professionals. I am sure you agree that these caregivers are incredibly important in the lives of people, especially adults, with developmental disabilities. They function as role models, cheerleaders, confidants, as well as teachers. Because these caregivers are so essential to the quality of life of people with developmental disabilities, we care about their health and wellbeing as well as the health of the adults they serve.

There is reason for concern about the health and well-being of the direct support work force. The average direct support professional earns between \$10 and \$12 an hour and many work several jobs yet still live in poverty. A slim majority (62%) have completed high school and about half come from minoritized racial or ethnic groups. Most (89%) are women; 25% are single mothers. As direct support professionals in the DD service system, they are working a job with limited opportunities for career advancement. The demographics of this group epitomize the social determinants of health including poverty, education, segregation, and social support if I can take a leap and say that single mothers risk social isolation.

It is not surprising, then, that the direct support professionals (DSPs) have poor health outcomes. Compared to the overall US population, DSPs are more likely to be overweight or obese (65% versus 38%) and to use tobacco (32% versus 16.8%). I agree with many of you here that there is a need to invest in this workforce and specifically in the health of this workforce because they are important and because their health has an impact

on the health of people with DD for whom they care

How could we improve the health of DSPs? Taking a page from other workforce investment efforts and suggest workplace wellness programs. There is a strong business case for offering workplace wellness programs. Health promotion programs for employees improve their health, reduce sick days, and lower health care costs. In fact, for every dollar spent on workplace wellness programs, employers can save up to \$6. Another advantage is that workplace wellness programs improve employee morale and loyalty to the company, which can only improve retention and job performance.

That is very interesting, you might be thinking, but it will be hard to convince DD service providers to invest in workplace wellness programs for DSPs. Not because they don't care about their employees, they do. But the unfortunate truth is that the high turnover rate among DSPs is an investment disincentive. The other serious flaw in this idea is that it is simply not feasible for the DSP to get paid while they are engaged in the health promotion program and not engaged in providing billable care to adults with DD. The profit loss margin in DD services will not allow it.

The health promotion needs of DSPs are not so different from the health promotion needs of adults with DD. Workplace wellness programs are not so different from health promotion programs developed for adults with DD. They basically address health literacy, health behaviors, and work environment. We wondered whether health promotion programs could be offered to adults with DD and to their direct support staff together. That way, the DSP could still bill for their time engaged in the program.

Better Together

A group of us at the Ohio State University Nisonger Center piloted this approach using a Cooking Matters curriculum that was designed to be offered to food insecure communities. The program teaches about nutrition and healthy eating in didactic but also offers hands on cooking instruction and practice. Each week participants make a meal together and then went home with the recipe and all of the ingredients needed to make the same meal at home. We enrolled adults with DD and direct support professionals. All of the participants really loved the class and we were

surprised by the enthusiasm of the DSP participants. They reported learning a lot and changing the way they cook for their own families.

Inclusive health promotion programming has several advantages. First, having adults with DD participate alongside their direct support professional could foster shared goals of making healthy choices. Second, a critical mass of adults striving to improve their health could foster a health-supporting culture in the environment. Finally, it may just make it financially possible for DD service providers to offer workplace wellness programs and improve the health of their DSP workforce.

Finally, I want to thank all of you for your attention today and say that I look forward to continuing my service as the president of the board and to seeing all of you at future meetings!

References

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