

ISSUE BRIEF

Health and Wellness for People with IDD

December 2015

People with intellectual and developmental disabilities (IDD) have begun to participate in their own health promotion and disease prevention activities and are learning how to advocate for their own health. Over the next decade, a coordinated approach to research, practice, and education, along with a policy agenda for health and wellness activities, can result in improved health and wellness outcomes for people with IDD.

► Introduction

This brief describes the research goals identified by the invited participants of a strand charged with addressing health and wellness for people with IDD at the *National Goals Conference* in Washington, DC on August 6-7, 2015.

Research, education, and practice activities increasingly focus on assessing the health status of people with IDD; developing, testing, and implementing evidence-based health and wellness initiatives for people with IDD; and training of health care professionals to decrease health disparities.

Currently, people with IDD who live in community-based settings tend to have high rates of obesity, low fitness levels, and lead sedentary lifestyles. They experience many factors related to negative determinants of health (e.g., individual behavior, genetics, environmental exposures, social circumstances, lack of access to healthcare), which result in decreased life expectancy, increased morbidity, and greater rates of co-occurring conditions (Scheepers et al., 2005).

► Need for Research

Given a growing body of research evidence documenting the overall health of people with IDD living in the community, a need exists to promote disease prevention, supports for wellness, and health and functional outcomes with this population. Coordinated research is critical to develop and test health and wellness practices for people with IDD that can be implemented in community-based settings.

► Health Surveillance Research Goals

Research designed to systematically collect and aggregate health-related data of people with IDD is paramount to understanding diseases, informing health initiatives for people with IDD, and appropriately allocating funds and resources.

► Information Exchange Research Goals

Research to develop and understand effective methods for collecting, mining, and disseminating a repository of health and wellness information and data is essential. It is equally imperative to ensure that evidence-based health and wellness information is broadly available and easily accessible by people with IDD, their families, health care and support providers, educators, policy makers, and researchers.

► Community-Engaged Research Goals

Community engagement can improve the quality of research and significantly increase the relevance to and involvement of people with IDD and their families. While a

IMPACT

Stephen is a young man receiving services from a community-based organization that launched an evidence-based health promotion program to address emerging health concerns among people with intellectual and developmental disabilities (IDD). Stephen was not initially interested in participating in the new health promotion program. After observing the classes, he approached the instructors and asked to participate. Since he was too late to join the class that had already started, he recruited others to begin a new one. Upon completing the program, Stephen wrote a poem, "The Way I Used to Be," to express his experiences in learning about his body, developing skills to take care of himself, and becoming motivated to reach new goals (e.g., exercising, eating healthy foods, losing weight). With the support of the program and others, Stephen was able to make healthy changes to his own behaviors.

growing number of studies support interventions to promote health, reduce health risks, and prepare adults to engage in preventive health practices, health disparities persist among people with IDD. People with IDD, along with their families and support providers, are essential to research processes that address the needs of people with IDD; produce rigorous, generalizable results; reduce health care disparities; and inform policies and practices that improve health outcomes.

► Caregiver Health Research Goals

Evidence-based strategies for health and wellness programs and services are critical for families and others who provide the majority of long-term supports for people with IDD. As the health of people with IDD is "interdependent" with those they rely on for supports, research to identify the best practices for caregiver health is crucial to assure optimal outcomes for people with IDD.

► Models of Care Research Goals

Research designed to elicit outcomes of existing and emerging models of care and care delivery are essential to enable health care systems to enhance health care access and improve outcomes for people with IDD (Harder+Company Community Research, 2008).

► Training Research Goals

Research that examines training gaps and demonstrates solutions that can be implemented in pre-service and clinical settings is necessary to assure optimal health outcomes for people with IDD. People with IDD face substantial challenges in accessing appropriate health care services due to physical access barriers, lack of transition services across the lifespan, and training gaps among health care professionals in clinical issues faced by people with IDD (Hemm, Dagnan, & Meyer, 2015)

► Conclusion

People with IDD who live in community-based settings continue to have poorer health than their non-disabled peers. A coordinated health and wellness research agenda is essential for improving health behaviors and health outcomes people with IDD and demonstrating effective implementation strategies in community-based settings. The goals described here demonstrate a pathway for health and wellness research, policy, and practice for the next decade that will enhance the lives of people with IDD and those that support them.

► References

- Harder+Company Community Research. (2008). *A Blind Spot in the System: Health Care for People with Developmental Disabilities*. San Francisco, CA: Author.
- Scheepers, M, Kerr, M, O'Hara, D, Bainbridge, D, Cooper, SA, Davis, R, . . . Wehmeyer, M. (2005). Reducing health disparity in people with intellectual disabilities: A report from health issues

special interest research group of the international association for the scientific study of intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 2(3-4), 249–255.

Hemm, C. Dagnan, D. Meyer, T.D. (2015). Identifying training needs for mainstream healthcare professionals, to prepare them for working with individuals with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 28(2), 98-110.

► Acknowledgements

Brief authors Jasmina Sisirak, PhD, and Beth Marks, PhD, both of the University of Illinois at Chicago; Lindsey Mullis, MS, University of Kentucky; and James Stephen Love, HealthMatters Program; gratefully acknowledges the members of the Health and Wellness strand for their contributions to the work of the *National Goals* conference, this policy brief, and other supplemental materials.

The Way I Used to Be

By James 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

This material was created with support, in part, by the American Association on Intellectual and Developmental Disabilities; the Association of University Centers on Disabilities; The Arc of the US, the National Institute on Disability, Independent Living, and Rehabilitation Research; the Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities at the University of Massachusetts Boston (Grant #90RT5028); the Research and Training Center on Community Living and Employment at the University of Minnesota (Grant #90RTT5019); and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago (Grant #90RT5020).

The views and opinions expressed in this document were generated by independent teams at the *National Goals* Conference held August 6–7, 2015 in Washington, DC. They do not necessarily reflect the official policy or position of any of the planning partners or the National Institute on Disability, Independent Living, and Rehabilitation Research—endorsement by the federal government should not be assumed.