Introduction to the Special Issue on Health, Health Promotion, and Health Care for People with Intellectual Disability

Corresponding Author:
Jean P. Hall, Ph.D.
jhall@ku.edu
University of Kansas
Institute for Health and Disability Policy Studies
1000 Sunnyside Avenue, Room 1052
Lawrence, KS 66045

INTRODUCTION

Introduction to the Special Issue on Health, Health Promotion, and Health Care for People with Intellectual Disability

This special issue of Inclusion focuses on health, health promotion, and health care for people with intellectual disability (ID). The relationship between inclusion and health is bi-directional in that greater inclusion in one’s community is related to improved health and improved health facilitates increased participation and inclusion in the community. As Anderson et al. (2013) noted, gaps in the literature in regard to improving health for this population include a lack of trials of interventions for this population and a lack of data that allow for better comparisons between people with ID and those without. However, enhancing knowledge in each of these areas would help enable the identification and implementation of effective supports for health.

For many years, the federal Centers for Disease Control and Prevention (CDC) has funded state Disability and Health Programs to address health issues for people with disabilities. In 2016, CDC specifically targeted improving the health of people with mobility impairments and/or intellectual disability for these state-based programs. CDC required all nineteen state programs to implement interventions addressing at least one of the following health areas: cardiovascular disease, diabetes, physical activity, nutrition, healthy weight, tobacco use and exposure, hypertension, or oral health. In addition, CDC chose a subgroup of state programs to participate in an effort to access and analyze Medicaid data to better understand the health, health care experiences and outcomes of people with ID. Notably, all these CDC-funded programs were required to include people with disabilities in all aspects of their program planning and implementation such as advisory boards, planning committees, and project staff (CDC, 2016). As many researchers note, inclusion of people with disabilities in the development of programs
INTRODUCTION

that directly affect them is a fundamental, though often overlooked, element of public policy (e.g., Iezzoni & Long-Bellil, 2012; McDonald & Raymaker, 2013). As the articles in this issue affirm, meaningful progress on improving the health of people with ID is unlikely to be made unless they are involved in all stages of intervention development and testing.

In addressing health issues for people with ID, the articles in this issue present national data comparing people with and without ID on measures of health status, access to health care and community participation and findings from CDC Disability and Health Programs in Kansas and Massachusetts. The first article by Hall and Kurth sets the stage for why interventions are needed to improve health for people with ID. It uses national survey data to first demonstrate that Americans with disabilities overall experience poorer health than Americans without disabilities and, further, that Americans with ID fare worse than their peers with other disabilities on many measures, including overall self-reported mental health status, having been refused services by a medical provider, and feeling socially isolated.

The second article, by Kurth and Hall, and the third article, by Nary and Bruns, discuss interventions developed by the Kansas Disability and Health Program in partnership with Kansans with ID. The first intervention, “Feeling Good About Your Smile,” is an oral health intervention designed to increase awareness of the importance of oral health on overall health, good oral health behaviors, and healthy foods. Initial feedback from consumers has been positive and pre-/post- test data indicate gains in knowledge among participants. The second intervention, “Stoplight Healthy Living,” is intended to improve nutrition and increase physical activity for participants with ID. Stoplight shows promising initial results, with the need for some modifications based on feedback from participants and support staff. These two articles
INTRODUCTION

demonstrate that targeted health interventions for people with ID can be successful and that participants need to be involved in all stages of their development.

The final article by Lauer, Nicola, Warsett and Monterrey of the Massachusetts Disability and Health Program uses state Medicaid data to highlight mental and behavioral health conditions that are prevalent among people with ID and how they result in increased emergency department use for this population. The authors make a compelling case that additional research is needed to better understand the exact nature of the mental health conditions experienced by people with ID, that medical and allied health professionals need additional training in this area, and that availability of interventions and services in the community need to be expanded in order to prevent conditions from escalating to emergency status. In general, they conclude that public health professionals still have much work to do in this area to support improved mental health outcomes for people with ID.

This collection of articles is noteworthy in that each focuses on the health of people with ID living in the community. As such, they are a testament to the progress made by people with ID and advocates. Fifty years ago, much of the health care provided to people in this population was the purview of large institutions where many of them lived. While deinstitutionalization has had a profound and positive impact on self-determination and quality of life for people with ID, community-based and public health care systems still need support in providing appropriate services and supports to this population. Efforts like those of the state Disability and Health Programs are one example of how this support can occur.
INTRODUCTION

References


