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Health services, health promotion, and health literacy: Report from the State of the Science in Aging with Developmental Disabilities Conference

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Abstract

Background: This article summarizes the proceedings of the Health Services, Health Promotion, and Health Literacy work group that was part of the "State of the Science in Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Living." Participants aimed to identify unmet needs related to health and health care and to determine training, research, and policy needs addressing the demands for increasing health care services and resources, end-of-life and palliative care, and health literacy.

Methods: Key issues addressed included (1) major health-related disparities for adults with intellectual and developmental disabilities (I/DD); (2) the impact of internal and external factors on health care services and resources, end-of-life and palliative care, and health literacy for adults with I/DD; and (3) frameworks that can be used for understanding and promoting health care services and resources, end-of-life and palliative care, and health literacy.

Results: Group participants identified research and practice needs related to primary care, health promotion, disease prevention, illness care, end-of-life issues, and palliative care.

Conclusions: Health care services for adults with I/DD may occur in a variety of settings including community-based programs, private practices, and community-based agencies supporting persons with disabilities. Major gaps relate to health disparities due to underdiagnosis, misdiagnosis, less chance of receiving prompt treatment, limited access to providers, lack of research information, transportation barriers, and lack of accessible medical equipment. Models of care including variables related to translation, sustainability, accessibility (e.g., affordability, availability), acceptability (e.g., culturally relevant, satisfaction), and equity need to be developed.

Keyword: Intellectual and developmental disabilities; Health; Literacy; Palliative care

Introduction

Reducing health disparities of persons aging with intellectual and developmental disabilities (I/DD) is emerging as an explicit area of focus in the public health arena and is increasingly being included in national health goals for people with disabilities [1]. A need exists to address access to quality services related to primary care, health promotion, disease prevention, health literacy, and training among persons with I/DD, families, and professional caregivers, and health care providers.

This paper presents the results of the work group that focused on addressing health services needs among persons with I/DD. The first day of the conference, researchers presented on topics addressing health status, health services, health literacy, and palliative and end-of-life (EOL) care. Following these presentations, an expert work group composed of researchers, health care providers, persons with

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I/DD, and policymakers examined the existing knowledge in relation to health care services and resources, dimensions of care, health literacy, and palliative and EOL care. Using a consensus decision-making process key issues related to health status and health care services for people aging with I/DD were identified. On the second day, the work group aimed to develop recommendations addressing the unmet needs related to health status and health care disparities and to determine training, research, and policy needs addressing the demands for increasing health care services and resources, EOL and palliative care, and health literacy. The symposium addressed the following questions to develop a research and policy agenda incorporating health care delivery interventions and systems that improve health outcomes and increase community engagement:

1. What are the major health-related disparities for adults with I/DD?
2. How do factors, including access, acceptability/satisfaction impact health care services and resources (primary care and health promotion), EOL and palliative care, and health literacy for adults with I/DD?
3. What frameworks can be used for understanding and promoting health care services and resources, EOL and palliative care, and health literacy?

Study group discourse

Health-related disparities

As many people with I/DD can now expect a longer life span that parallels the general population in the United States, research suggests that they may age differently based on the nature and severity of their disability, other coexisting health problems, and chronic health conditions. This presents unique challenges to health care professionals as we develop health systems aimed at supporting adults with I/DD to achieve optimal health status.

Several issues may impact morbidity and mortality for persons with developmental disabilities, such as chronic respiratory infections, heart conditions, infections, reduced mobility, epilepsy and refractory seizures, dependency in eating and toileting, and severe and profound intellectual disabilities. Cardiovascular disease (CVD) is one of the most common causes of death among aging adults with I/DD [2-6]. Data also demonstrate higher rates of obesity and poor nutritional habits among adults with I/DD compared to the general population [3,7-9].

Evidence suggests that people with DD experience earlier age-related health conditions, including incontinence, swallowing difficulties, sensory losses, adaptive behavior losses, and cognitive declines [10]. For example, people aging with cerebral palsy (CP) may have increased issues related to bowel and bladder dysfunction that is associated with urinary tract infections, respiratory compromise and infections, oral motor problems and dental disorders, fractures, fatigue, gastroesophageal reflux, spasticity, pain, arthritis, musculoskeletal deformities, decreased ambulation, and progressive cervical spine degeneration [11]. Persons aging with CP and epilepsy who use psychotropic and antiseizure medications on a long-term basis have a higher risk of developing osteoporosis and tardive dyskinesia. This risk is often compounded by limited physical activity and diets limited in calcium and vitamin D.

Persons with Down syndrome have a higher prevalence of early-onset Alzheimer disease compared to the general population, and they experience hypothyroidism and sleep apnea more frequently [12]. People with I/DD may experience an increase in chronic conditions related to altered postures, immobility, long-term use of medications, and poor nutrition. While early detection of disease risk may help to reduce such disparities, many adults often do not participate in preventive health care at recommended levels. Women with I/DD who live in the community are less likely than their nondisabled peers to receive preventive health screenings (e.g., mammography and Pap smear) [13]. Because of different developmental trajectories and limitations in communication and cognitive skills, health care delivery to people with I/DD is often ineffective or absent [2]. Often the result is underdiagnosis, misdiagnosis, or less chance of receiving prompt treatment.

Factors impacting health care services

Primary care and health promotion

As health systems resources decrease, the increased time pressures are especially problematic for adults with I/DD who often need extra time for examinations, tests, procedures, and communication. More information is often needed to reduce their fears and to help them make informed health care choices. Early education combined with opportunities for lifelong learning can help people develop the skills and confidence they need to adapt and maintain healthy lifestyles as they age. Improved health education and health literacy represent a critical component for people to gain control over their health and manage chronic conditions [14]. Heller and Marks [13] report that to achieve higher health status levels among persons with disabilities, caregivers must also be educated about health-related issues. With the unique needs and concerns of persons with I/DD, including limited access to providers, lack of research information, transportation barriers, lack of accessible medical equipment, and limitations of insurance, models of care need to be developed that include variables related to accessibility (e.g., affordability, availability), acceptability (e.g., culturally relevant, satisfaction), and equity [6,15].

Care for people with aging with I/DD is influenced by existing negative attitudes toward aging and disability, fewer social supports, lack of understanding regarding unique needs, difficulty accessing appropriate services, and increased risk of abuse and neglect. Primary care