Health and Wellness Strand: Recommendations From National Goals Conference 2015

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Abstract
Although a variety of health and wellness initiatives have emerged in the past decade, people with intellectual and developmental disabilities (IDD), their caregivers, and advocates still are facing remarkable challenges in staying healthy and receiving appropriate health services. The National Goals 2015 Conference provided a unique platform and an opportunity to summarize the current state of knowledge, identify national goals in research, practice, and policy, and set the stage for the future directions in health and wellness in IDD field. This article presents an outline to improve the health of people with IDD. The goals identify major health and wellness issues and solutions proposed by a group of disability researchers, policy specialists, advocates, health care providers, and service providers with the aim to set forth an agenda for national, state, and local action to improve the health of people with IDD and include them fully in appropriate health systems.

Key Words: health; wellness; health care; surveillance; caregivers; models of care

What Do We Know About Health and Wellness?
A variety of health and wellness initiatives have emerged in the past 15 years for people with intellectual and developmental disabilities (IDD) following three significant documents: (1) the Surgeon General’s 2002 Closing the Gap: A National Blueprint to Improve the Health of People With Mental Retardation (U.S. Department of Health and Human Services, 2002), (2) The Surgeon General’s 2005 Call to Action to Improve the Health and Wellness of Persons With Disabilities (U.S. Department of Health and Human Services, 2005), and, (3) the 2007 Institute of Medicine report (Institute of Medicine, 2007). Although people with IDD are living longer than their peers with IDD of previous generations, they are still experiencing poorer health and earlier onset of age-related conditions than their peers without IDD (Bittles et al., 2002). Currently, adults with IDD who live in community-based settings have high rates of obesity, low fitness levels, and lead sedentary lifestyles (Melville, Hamilton, Hankey, Miller, & Boyle, 2007; Rimmer & Yamaki, 2006; Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998; Yamaki, 2005). The literature documents a “lack of intervention trials, replications of successful approaches, and data that allow for better comparisons between people with and without IDD living in the same communities” (Anderson et al., 2013, p. 385). A constellation of issues related to negative determinants of health (e.g., individual behavior, genetics, environmental exposures, social circumstances, lack of access to healthcare) are related to the decrease in life expectancy, increased morbidity, and greater rates of co-occurring conditions for people with IDD (Scheepers et al., 2005). Leveraging the intent of Affordable Care Act (ACA), we have a call to action to promote wellness and health, disease prevention, health and function, self-direction,
and quality of life of people with IDD. The aim of this article is to describe the methods and rationale used to develop health and wellness goals at the National Goals 2015 Conference held in Washington, DC on August 6–7, 2015 and address the implications of the health and wellness goals developed.

Developing the Goals

The Health and Wellness strand plenary was attended by 14 disability researchers, policy specialists, advocates, health care providers, and service providers as a part of the 2015 National Goals Conference. The purpose of the plenary was to emphasize the vision for the future and leadership of research, practice, and policy in health and wellness for people with IDD. The plenary was structured around eliciting participant responses in high priority areas: (a) established research findings related to health and wellness; and (b) operationalization of constructs and instrumentation, methodological issues, and other related research challenges determining the critical implications for policy and practice. Each priority area was approached integrating the six existing goals from the 2002 Closing the Gap report (U.S. Department of Health and Human Services, 2005) which included the following topics: (1) health promotion and community environments, (2) knowledge and understanding, (3) quality of health care, (4) training of health care professionals, (5) health care financing, and (6) sources of health care.

Health and Wellness Strand Goals

Based on the plenary discussion, the health and wellness strand recommended the following six goals:

1. Information Exchange
To develop and understand effective methods for collecting, mining, disseminating a repository (toolbox, treasure chest) of health, wellness and health care information and data, which incorporates technology and Universal Design with a multimodal approach to diverse community audiences (e.g., people with IDD, families, practicing professionals and other licensed and unlicensed and paid and unpaid caregivers, educators, policy makers, researchers) across all community sectors.

2. Community Engaged Science
To significantly increase the influence and involvement of people with IDD and involve families and caregivers in health research, practice, and policy.

3. Health Surveillance
To ensure that health surveillance activities identify and include the diversity of all people with IDD.

4. Caregiver Health
To develop and implement evidence-based strategies for health and wellness programs and services for families and service providers.

5. Models of Care
To identify, document, and compare the efficacy and effectiveness of existing models of community-based health care services (e.g., specialized clinics for people with IDD, managed care organizations, health homes, university-based health clinics, physician services agreements, and more recently the Federally Qualified Health Centers, FQHCs), specifically looking at improved health outcomes including patient centered outcomes and cost of care.

6. Training
To provide and improve training that increases cultural and clinical competence of medical and health and wellness professionals to provide optimal health care and health-related services to people with IDD across the lifespan with an emphasis on adults.

Implications

The previous goals aim to challenge the framing and the types of questions being asked and to develop best practices and innovative strategies for use in current programs and services. Following, we provide rationale and suggestions for realizing each goal.

Information Exchange
The classical pathways of translating original research to routine practice may take up to two decades (AHRQ, 2001). Sluggish knowledge translation of innovative findings, trainings, and programs is a major hurdle to improving health and health care of people with IDD. Development of a health and wellness information
exchange, guaranteeing access to online resources, and the use of smart technologies would help accelerate the impact of research and improve health outcomes, quality, effectiveness, efficiency, and cost of serving this population. The health and wellness information repository would provide (a) open access to research outputs (e.g., innovative health and wellness programs, best practices, new findings, etc.); (b) policy and practice monographs and reports; and (c) promising technology that inform best practices for facilitating health care delivery, health advocacy, inclusion, and self-determination for people with IDD, their families, and supports. Similar to the Cochrane model (http://www.cochrane.org/), creating an electronic center that can systematically review empirical, grey, and experience-informed literature; collect community based practices and programs in real-time; and provide accessible information, would ensure quick knowledge translation pathways linked and tailored to specific groups including advocacy groups (e.g., People First, SABE, The Arc, Easter Seals), families, support groups, health professions (e.g., American Association of Colleges of Nurses, American Colleges of Physicians), AARP, and non-traditional venues (e.g., faith-based organizations, pharmacies, and community businesses).

Community Engaged Science
People with IDD often have little input into the way their health and health concerns are perceived and defined. However, their health is greatly affected by definitions and perceptions of their health and health status. Conceptualizations of health by people with IDD may differ from their peers without IDD by virtue of their life experiences. Understanding the concept of health and wellness from the perspective of people with IDD provides a foundation for all health care services research.

Increasing the representation of people with IDD as research participants is essential, in both general population research and research specific to people with IDD. Shifting research methodologies from the ethically and scientifically questionable practice of data collection via proxy and the tendency to exclude people with IDD as a form of protection is imperative (Brooker et al., 2014; Feldman, Bosett, Collet, & Burnham-Riosa, 2013; Iacono & Carling-Jenkins, 2012; McDonald & Raymaker, 2013; Northway, 2014). Although this shift invites ethical and social challenges related to potential concerns about undue influence and the ability to make an informed decision (Becker, Roberts, Morrison, & Silver, 2004; Cameron & Murphy, 2007; Fisher, 2003; Fisher, Cea, Davidson, & Fried, 2006; Iacono & Murray, 2003; Totsika, Hastings, Vagenas, & Emerson, 2014), a need exists to continue working with community members to identify policies and practices that facilitate the respectful, safe inclusion of people with IDD in research. Utilizing principles of community-based participatory research (CBPR) and community-based participatory action research (CBPAR) approaches to provide a model for including people with IDD, families, and other community supports would promote understanding, involve community, identify community-relevant issues, and focus on problem-solving and societal change (Hills, Mullett, & Carroll, 2007; McDonald, 2012; McDonald, Kidney, & Patka, 2012; McDonald & Raymaker, 2013; McDonald, Schwartz, Gibbons, & Olick, 2015). Last, people with IDD have been fundamentally excluded from participating in large-scale survey research. Difficulties in communication and understanding are considered too large of an obstacle to include this population in research (Tourangeau, Edwards, Johnson, Wolter, & Bates, 2014), a contention with which we disagree. The purpose of developing methods for accessing hard-to-reach populations who may not have knowledge or resources to connect with existing services is to identify and develop successful models that can be utilized by people who are underserved or underrepresented. Methodologies that can be utilized to improve surveillance and inclusion of people with IDD in research include two-stage sample, indirect sampling, time-location sampling, respondent driven sampling, and snowball sampling (Marpasat & Razafindratsima, 2010; Wilson et al., 2013). For example, the aforementioned methodologies can help reach people who are living with their families and not receiving any services, or those who may be living in poverty or living within an immigrant community.

Health Surveillance
The purpose of health surveillance is to monitor the health status and health behaviors of people with IDD and their supports to (a) provide a transparent base of evidence, (b) set priorities, (c)
plan and implement programs, and (d) evaluate the impact of programs and interventions that promote and protect health. Existing large datasets through Special Olympics (SO) and the National Core Indicators (NCI) provide robust data for a subset of the population that may not be generalizable to all people with IDD. For example, it is estimated 74% of people with IDD do not use any developmental disability services, and only people using state-funded services are in the NCI sampling frame. Also, SO data cannot extrapolate who is living where and link it to health care delivery systems. Within the large population-based surveys in the United States, isolating data for people with IDD is limited, primarily due to lack of a common operational definition of IDD. Adding new questions to existing surveys related to the health of people with IDD remains challenging. The recommendations on a common operational definition of IDD for national health surveillance can be found in the Developing an Operational Definition of Intellectual Disability for the Purpose of National Health Surveillance report (Bonardi & Lauer, 2011). Three components of the definition have been offered including (a) conceptual (population definition), (b) operational definition, and (c) a series of pathways by which subpopulations could be identified. Surveillance efforts could be linked to the current national longitudinal studies (e.g., National Longitudinal Study of Adolescent to Adult Health) by adding a common operational definition of ID to identify the IDD population. Also, linkage with other data sources (e.g., MEPS, State Inpatient Databases, State Emergency Department Databases) would provide more comprehensive understanding of lifespan health and the impact of life transitions on health.

Caregiver Health
The health and safety of unpaid and paid caregivers has been recognized as a significant concern. Caregivers are challenged with multiple occupational hazards including (1) physical (e.g., ergonomic from lifting and repetitive tasks, poor body mechanics, limited flexibility, falls, physical attacks from “acting out,” adverse effects from shift work, including sleep deprivation), (2) biologic (e.g., bacterial infections, viral infections, fungal infections, bloodborne pathogens), and (3) psychosocial stress (e.g., verbal threats and abuse). With the link of caregiver occupational hazards to poor health, emotional problems, unhealthy lifestyles, quality of life, marital and family problems, ensuring caregiver safety and health is a critical unmet need for job success (Khatutsky et al., 2011) and improved quality of services, continuity of care, and health outcomes for people with IDD (Hickey, 2014). Evidence-based strategies for health and wellness programs and services for families and service providers is critical in building collective efficacy given the culture of interdependency in the lives of people with IDD who often rely on their family members and multiple professionals for support their entire lives.

Models of Care
Evidence demonstrates that greater emphasis on primary care can likely lower the costs of care, improve health through access to more appropriate services, and reduce the inequities in the population’s health (Starfield, Shi, & Macinko, 2005). Several mechanisms may account for the beneficial aspects of primary care including the following: (a) greater access to needed services, (b) better quality of care, (c) a greater focus on prevention, (d) early management of health problems, and (e) coordination of primary care with appropriate specialist care.

As significant changes occur within the U.S. health care structure, new models of community-based health care services are being developed in an attempt to fill the gaps in services experienced by underserved and underrepresented groups such as people with IDD (Harder+Company Community Research, 2008). Models of care range from specialized clinics for people with IDD, managed care organizations, health homes, university-based health clinics, physician services agreements, and more recently the Federally Qualified Health Centers (FQHCs; Harder+Company Community Research, 2008). Each of these models includes a variety of services for people with IDD who often have complex behavioral and physical health needs. They often also include key components of robust services for IDD community (e.g., integrated clinic with all specialists at one site available in a specific time, care coordinator, links patient and family with resources, patient-centered care, culturally relevant care, services combined with health profession student training, community clinicians and caregivers). Each of these models of care are not mutually exclusive and may overlap. A need exists to evaluate the various
models for a personalized approach for managing chronic conditions, supporting self-management, and building skills for collaborative decision making among people with IDD across the lifespan. Experts in the IDD field need to participate on research review committees for proposal applications to ensure that people with IDD are included in models of care research projects (e.g., PCORI, AHRQ).

Training—Culturally Congruent Instruction

Much of the training of health care professionals continues to focus on acute health care needs for people with IDD rather than on (a) culturally congruent knowledge, skills, and values related to disability, and (b) determinants of health including promotive, preventive, and primary health care areas. Within health care services, reports continue to document the (a) lack of training for health care professionals across all disciplines and problems related to attitudinal barriers, (b) policies devoid of universal design, (c) issues with communication barriers, (d) lack of transition from pediatric to adult care providers and care during transition periods across the lifespan, and (e) inadequate access to appropriate adult care services. Three areas of need for training health providers working with people with IDD have emerged: (1) communication training with people with IDD, (2) education on IDD and local IDD services, and (3) profession-specific need (Hemm, Dagnan, & Meyer, 2015). A need exists for requiring a core disability curricula for accreditation and receipt of Federal funding for preservice training among physicians, nurses, and allied health providers, along with demonstrated competencies for licensure (Havercamp & Scott, 2015). Additionally, this core disability curriculum could be tailored to profession-specific information and resources.

Although people with IDD can benefit from many services provided to the general population by enhancing their access to such services, we continue to have large gaps in a variety of specific types of services. Health education for people with IDD often does not include information as to the interaction of their disability with health promotion activities. With proper accessible tools and multimodel communication strategies, people can more easily obtain, process, and understand basic health information and services needed to make appropriate health decisions. Health care providers require training to increase understanding of health-related issues for people with IDD including (a) social determinants of health, (b) transition services across the lifespan, (c) sexuality, (d) reproductive health, (e) human rights to access life-saving interventions, (f) right to life, (g) food access/food security, (h) disaster preparedness, and (i) violence prevention and intervention services.

Conclusion

The intent of the six identified goals is to 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 their supports. Although significant progress has been made, considerable work remains to ensure the best health outcomes for people with IDD and their supports by (a) assuring access to health care, programs, and services for all people with IDD and their caregivers, and (b) providing robust training of health care providers. Future efforts to improve health and prevent disease for people with IDD must generate relevant evidence and translate research findings quickly and effectively to inform local, state, and national policies and services that affect the lives of people with IDD and their caregivers.

References


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