



STARFIELD SUMMIT

...where primary care research inspires policy and practice

STARFIELD HEALTH EQUITY SUMMIT ISSUE BRIEF

Theme: Vulnerable Populations

Title of IGNITE Presentation Topic:

People with Disabilities (Developmental and Intellectual Disabilities)

Why This Is an Important Topic to Address (brief description):

People who have developmental and intellectual disabilities (DD/ID) are a unique and medically distinct population who have both the right and natural inclination to live in typical settings in the community. While they may have financial access to medical resources through government payers, that access is limited by physical, linguistic, cultural, and administrative barriers and the content of care received is adversely impacted by deficits in attitudes, skills, and knowledge among health care professionals. Most people with ID/DD rely on others for assistance with daily activities, so the quality, configuration, and funding of the broader service system is a critical element of health and wellbeing. People with DD/ID rank high in poverty, unemployment, social isolation, and other health determinants. Race and ethnicity amplify some disparities. People with DD/ID constitute 2% of the US population, but many of the factors that affect their health are generalizable to the health status of people who have acquired disabilities caused by the effects of chronic illness, injury, aging, and other factors, which represents 19% of the US population. This population also experiences significant disparities.

What We Think We Know (Bulleted evidence + Seminal references):

- ~ Average age of death for people with DD/ID: women =62.5 (general population = 81.1), Men =59.9 (general population=76.3). This is multifactorial.
- ~ Sepsis, pneumonia, and dementia deaths are 50-100% higher than the general population
- ~ Women with ID/DD are 2-3 times less likely to have regular Pap smears and mammograms than women without disabilities or who have acquired disabilities
- ~ 45.1% of people with DD/ID reported no physical activity in the month they were surveyed and 31.6% indicated inadequate social support compared to 10% and 7.1% in the "no disability" population
- ~ African American adults with DD/ID are less likely than white individuals with DD/ID to have physical exams, dental care, and influenza vaccine
 - Family income is a more powerful predictor of these disparities than race and ethnicity

-Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J.* 2015 Apr;8(2):165-72.

-AAMDMD, Health Disparities Consensus Statement, <https://aadmd.org/articles/health-disparities-consensus-statement>

-V. Bradley; Exploring Health Disparities Among People with Intellectual and Developmental Disabilities. What Are the Issues and Do Race and Ethnicity Play a Role?,

http://www.nationalcoreindicators.org/upload/presentation/FINAL_NASDDDS_2014_Health_Disparities.pdf

Questions for Group Discussion

Questions to Address in Group Discussion:

- ~ What does it mean to have a disability? Is this a medical condition, social construct, or something else? Are people with disabilities a “special” population?
- ~ How can people with DD/ID, their families, direct care workers, and advocates be more actively included in efforts to reduce disparities in preventive services, medical outcomes, and social determinants of health?
- ~ What are the implications of the findings that race, ethnicity and income intensify health disparities for people with DD/ID and how can this be addressed?
- ~ How can health care professionals and administrative staff improve their ability to provide medical care for people with DD/ID and better organize systems of care to meet their needs?
- ~ What are the “right” indicators of health outcomes for people with DD/ID? How can research be better structured? How can complex issues of informed consent be successfully navigated?
- ~ The population of people who have disabilities of all types is increasing and it is known that they experience significant disparities in health status. How can these disparities be addressed and what are the implications of this for the configuration of the health care system in the future? What lessons can be learned from the experience of people with DD/ID?

Implications for Action (In Research, Education, Policy, Practice and Organizational and Community Action):

- ~ People with DD/ID should be formally recognized as constituting a “medically underserved population” by the HRSA and other federal agencies, and receive the consideration, benefits, opportunities and assistance provided to populations with that designation.
- ~ Curricula for health professions students and resources for practicing clinicians should include education and point of care information about medically specific issues related to DD/ID to improve care.
- ~ Methodologies for quality improvement should be applied to reduce disparate causes of mortality and to improving access to preventive services for people with DD/ID.
- ~ Research should be focused on the development of more evidence-based clinical guidelines and the dissemination of best practices to enhance health promotion, disease prevention, and specific treatment for people with ID/DD.
- ~ Health systems, public health resources, and individual clinicians in conjunction with payers should have accountability for the outcomes of care for people with DD/ID, including quality of life measures. This is particularly significant as major changes in Medicare, Medicaid, and public funding of disability-related resources at the federal, state, and local level are contemplated.
- ~ Family members and direct care workers, who have essential roles in the daily lives of people with DD/ID, should be valued for the work they do and supported to be effective health partners.
- ~ People with DD/ID, their families, direct care workers, and advocates must be integrally involved in all elements of efforts to reduce disparities and reshape the care system to better serve their needs.