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Research Paper

National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities

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Abstract

Background: People with disabilities experience worse health and poorer access to health care compared to people without disability. Large-scale health surveillance efforts have largely excluded adults with intellectual and developmental disability. This study expands knowledge of health status, health risks and preventative health care in a representative US sample comparing the health of adults with no disability to adults with intellectual and developmental disability and to adults with other types of disability.

Objectives: The purposes of this study were (1) to identify disparities between adults with intellectual and developmental disability and adults with no disability and (2) compare this pattern of disparities to the pattern between adults with other types of disability and adults without disability.

Methods: This study compares health status, health risks and preventative health care in a national sample across three groups of adults: No Disability, Disability, and Intellectual and Developmental Disability. Data sources were the 2010 Behavior Risk Factor Surveillance Survey and the National Core Indicators Consumer Survey.

Results: Adults with disability and with intellectual and developmental disability were more likely to report being in poor health compared to adults without disability. Disability and intellectual and developmental disability conferred unique health risks and health care utilization patterns.

Conclusions: Significant disparities in health and health care utilization were found for adults with disability and developmental disability relative to adults without disability. Disability training for health care providers and health promotion research that identifies disability as a demographic group is needed.

Keywords: Developmental disability; Disability; Health surveillance; Disparity

People with disability experience worse health and poorer access to health care than the general population. Health inequity has been defined as differences that are not only unnecessary and avoidable but are also considered unfair and unjust.[1,2] People with disability experience inequities in many aspects of health and health care. The inclusion of disability items on major health surveillance protocols such as the Behavior Risk Factor Surveillance Survey opened an entire disability and health field whereby disparities in health outcomes and access to health care are addressed. This study compares the health of adults with no disability to adults with intellectual and developmental disability (IDD) and to adults with other types of disability in a representative US sample.

People with disability are vulnerable to high rates of health risks including physical inactivity,[3] obesity,[4,5] smoking,[6] and inadequate emotional support.[7] They also experience high rates of chronic health conditions including diabetes,[8] high blood pressure, arthritis, chronic pain, and heart disease.[7] In addition, this population is vulnerable to disability-related health conditions that can be severely detrimental to functioning and quality of life.[9,10] These conditions vary by type of disability and may include pressure ulcers, overuse injuries, dysphagia, and mental health problems.[11,12] This health risk phenomenon has been described as producing a ‘‘thinner margin of health’’ for people with disability.[13]

Despite having a greater need for health care, people with disability have decreased access to needed health care services. Disparities have been found in cancer screenings, oral health, and cholesterol checks.[7,14,15] Disparities in health care access can be attributed to barriers unique to adults with

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disability.[16] These barriers include physical inaccessibility of health care facilities and exam rooms, communication difficulties with health care providers, lack of adequate medical information[17] and lack of knowledge and understanding of disability on the part of health care providers.[18–20]

Less is known about the health of adults with IDD. Large scale, well controlled health surveillance studies of adults with IDD are complicated by the cognitive impairment associated with IDD and the stigma associated with the condition that makes self-identification of disability status unlikely. Although large scale surveillance research is scarce, evidence does suggest that IDD may confer particular health risks, access to care barriers, and negative health outcomes.[21,22] Adults with IDD are more likely to have unhealthy weight,[23,24] epilepsy,[25] mental illness,[26] and overall poor health.[7]

Large clinic-based studies have found that access to routine health care was compromised in adults with more severe intellectual disability and those living in their family home.[27,28] People with IDD have a particular difficulty with transitioning to adult care services[29] and advocating for themselves in health care settings.[30] Disparities in access to health care for adults with IDD include lower rates of blood pressure checks, vision and hearing screens, cholesterol screens, and cancer screens.[31–34] Due to social stigma, lack of provider training, and insurance constraints, people with IDD in the United States may struggle to find health care providers who are able and willing to care for them.[35] In Australia as many as 90% of general practitioners reported that it was more difficult to provide quality care to patients with IDD and 16% stated that they would prefer not to treat people with intellectual disability.[36]

This study expands knowledge of health status, health risks and preventative health care in a national sample across three groups of adults: No Disability, Disability, and Intellectual and Developmental Disability (IDD). Disparities between the No Disability group and each of the two disability groups are highlighted. Overall health status is compared as well as health related risks including measures of tobacco use, obesity, physical activity, and emotional support. Preventive health indicators include physical exam, mammogram, pap test, prostate screening, flu shot, and dental visit.

Methods

Behavior risk factor surveillance system (BRFSS)

The Behavior Risk Factor Surveillance System (BRFSS) generated the surveillance data for the Disability and No Disability groups in this study. BRFSS is a telephone survey directed by the Centers of Disease Control and Prevention to track health conditions and risk behavior. All 50 states participate in this survey with over 350,000 interviews conducted yearly. For this study, the 2010 data for all states and territories is reported. In 2010, the BRFSS had two questions used to screen for disability (1) "*Are you limited in any way in any activities because of physical, mental, or emotional problems*?" (2) "*Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone*?" If respondents answered yes to either of these two questions, they were assigned to the Disability group. If respondents answered "no" to both questions, they were assigned to the No Disability group. BRFSS data was obtained from the Disability and Health Data System (DHDS), an interactive state-level disability data tool developed by the Centers for Disease Control and Prevention (CDC) to provide data on health and demographic indicators using the Behavioral Risk Factor Surveillance System and data on expenditures, http://dhds.cdc.gov.[37]

BRFSS data are routinely weighted to adjust the sample response by sex (male; female), race (white, non-Hispanic; non-white or Hispanic), and age (18–24; 25–34; 35–44; 45–54; ⩾65) to match the statewide sex-race-age distribution. This adjusts the sample for non-response or low response among certain demographic groups, such as young white males. The weighting procedure makes the BRFSS data representative of the total population of adults in the United States.

National Core Indicators Consumer Survey

Though national surveys, such as the BRFSS, include disability screener questions, they are unlikely to reach adults with IDD. People with severe intellectual impairments are unlikely to respond to telephone surveys and people with mild limitations living in the community may not self-disclose disability status. For these reasons, alternative methods of gathering information about the health of adults with IDD are necessary. The National Core Indicators (NCI) is a quality assurance protocol developed by the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services to evaluate service outcomes. Participants are randomly selected from all adults receiving developmental disability services and may include people with a range of disabilities such as intellectual disability, cerebral palsy, autism spectrum disorder, or epilepsy. The NCI Consumer Survey was used in this study, which collects information from three sources about adults with IDD. First, demographic and medical record information is obtained from case files. Secondly consumers are asked questions in a face-to-face interview where only responses from the consumer are accepted. Finally, in the third section of the survey, the individual with developmental disability and/or his or her caregiver is interviewed; if the individual is unable or unwilling to respond to the final section of the interview, a response from someone who "knows him/her well" is accepted. This approach of using records, self-report, and a third party responder is supported by Lunsky, Emery,