

# Adults with intellectual and developmental disabilities 'invisible' in national data

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People with intellectual and developmental disabilities (IDD) are often "invisible" in national population surveys that collect only the minimum data for disability, according to researchers at The Ohio State University

College of Medicine who are looking into the lack of data.

"Inadequate health surveillance of people with intellectual and [developmental disabilities](#) hampers our understanding of their health status, health determinants and health needs," said Susan M. Havercamp, associate professor in the Department of Psychiatry and Behavioral Health at Ohio State's College of Medicine.

Havercamp and Gloria L. Krahn of Oregon State University are the guest editors of a special issue of the journal *Intellectual and Developmental Disabilities* that explores why timely and [reliable data](#) is essential to identify health disparities, understand the causes and correlates of disparities and monitor progress in reducing them.

"In 2002, the U.S. Surgeon General's report, *Closing the Gap*, highlighted the need for better data on people with intellectual and [developmental disabilities](#). This concern persists today," said Dr. K. Craig Kent, dean of the College of Medicine. "These researchers explain how [public health](#) and policy planning for adults with IDD is imperiled by the lack of ongoing national surveillance data on the prevalence and health status of these individuals, and why this matters."

The Affordable Care Act of 2010 required establishing minimum data collection standards for disability status as well as for race, ethnicity, sex and primary language in all national population health surveys.

This requirement ensures that these marginalized groups are counted and reported in national data; however, the minimum standards don't allow for ready identification of persons with IDD within the disability group, said Havercamp, a researcher at The Ohio State University Wexner Medical Center's Nisonger Center.

Recent changes to two national surveillance systems—National Health

Interview Survey and the Survey on Income and Program Participation—eliminated questions that have been used to identify adults with IDD.

"Without specific questions that allow for ready identification of respondents with IDD, this population becomes invisible in the data," said Havercamp, who is also a member of Ohio State's Neurological Institute. "Changes to national health surveillance systems provide a challenge and an opportunity."

Havercamp co-authored three of the nine manuscripts published online in the journal. She also chaired the national surveillance workgroup that recommended four top priority areas and steps to improve health surveillance of adults with IDD. The workgroup encourages federal, state, public and private partners to work together so that adults with IDD will become visible in health [surveillance](#) data.

"Once adults with IDD are no longer invisible, empirical data will guide publicly funded services and supports that can better meet their [health](#) needs," Havercamp said.

**More information:** Susan M. Havercamp et al. What Matters in Population Health and How We Count It Among People With Intellectual and Developmental Disabilities, *Intellectual and Developmental Disabilities* (2019). [DOI: 10.1352/1934-9556-57.5.347](https://doi.org/10.1352/1934-9556-57.5.347)

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