

Researchers call for changing how medical research is done

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When it first passed 20 years ago, the American Disabilities Act offered hope for closing the health-disparities gap for people with disabilities, but differences still exist. Barring people with limiting physical issues from research studies may bear some of the blame, and researchers from Case Western Reserve University's Frances Payne Bolton School of Nursing want to change that restriction.

In a commentary for [Science Translational Medicine](#), Ann S. Williams and Shirley M. Moore ask researchers to rethink participation criteria that exclude people with sight, hearing or [mobility problems](#), or other [disabilities](#).

They suggest employing universal design methods like those adopted by classroom teachers to integrate children with disabilities in mainstream classrooms.

Some of those same tools - audio instructions or large print -- can accommodate people with disabilities. Without the participation of this population, the science is not all there, Williams said.

People with physical and mental challenges have some of the same health problems affecting the general population. For years, the one-size model of research based on how men suffered disease and weathered treatments was the norm until women and minorities became part of research. Scientific evidence shows that health-related differences do exist between men, women and minorities.

Williams suspects such differences will surface for the 47.5 million disabled, who make up 22 percent of the [American population](#), according to the U. S. [Centers for Disease Control and Prevention](#).

For example, Williams asked, "How much exercise does someone in a wheelchair need to be healthy?"

"When they ask someone how far they walk, in this case the walking can be how far the individual rolled the wheelchair," she said.

She wants to see "disability" added to "race" and "gender" in describing [study participants](#).

How major diseases, such as diabetes and [heart problems](#), impact people with disabilities will be unknown until they can participate, Williams said.

"We want to change that practice," said Williams, the study's lead researcher for the commentary, "Universal Design of Research: Inclusion of Persons with Disabilities in Mainstream Biomedical Studies."

Williams and Moore have started practicing and implementing those changes on the Case Western Reserve campus through the National Institutes of Nursing Research/National Institute of Health-funded center to promote Full INclusion of Persons with Disabilities (FIND Lab).

They are developing technologies and methods to include people with disabilities in research and provide a campus resource for training researchers on ways to adapt their research projects for the disabled.

The researchers are collaborating with the Cleveland Sight Center and Cleveland Hearing and Speech Center to make changes.

In late summer, they will open a lending library at Case Western Reserve with those tools that range from inexpensive magnifiers to help people read instructions, sound amplifiers, to more sophisticated computer programs that translate text into sound for the visually impair.

"We have concentrated primarily on people with hearing and sight problems," Williams said. "In the process, we have found these same technologies are applicable for people who can understand verbal instructions but cannot read."

"Universal Design is a way to change the way we do research," Williams said.

Provided by Case Western Reserve University

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