

## Where Are All The People With Physical Disabilities?

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**T**hirty years after passage of the Americans with Disabilities Act, people with physical disabilities remain largely invisible and unaccommodated in healthcare, receiving sub-par services and enduring high rates of preventable illness and premature death.

There are many reasons for this. One is that data reflecting the unique and specific needs of people with physical disabilities is rarely recorded or counted, and much of what is collected isn't very useful. For example, to some extent we can answer questions about the gender, age and employment status of people with physical disabilities, but we don't know how many of these folks who use wheelchairs or rely on home care to remain independent – critical data points for both emergency and long-term planning.

Research, analysis and data collection routinely treats people with physical disabilities as an indiscrete subset of other populations – usually the elderly, or people with intellectual or developmental disabilities – rendering them invisible and distorting policy decisions and funding allocations. The care needs of a 90-year-old man with dementia who rarely leaves home are quite different from those of a 27-year-old woman with a spinal cord injury who works in an office and plays wheelchair basketball on the weekends. Yet, due to the failure to collect discrete data on the needs of people with physical disabilities, the services available to these two very different individuals are identical under Medicaid, the nation's largest health insurers.

As just one of many examples of our data collection problem, the U.S. Census Bureau's American Community Survey (ACS) does include a few imperfect but potentially useful questions about disability. However, the ACS collects data from only a small number of Americans – with a target of just 3.54 million for 2018 – whereas the Bureau's Decennial Census, which aims to count everyone, contains no disability related questions.

Right now, we are living through a global pandemic. While disability per se does not increase the risk of contracting COVID-19, many people with physical disabilities are at higher risk of severe illness should they contract the virus due to preventable underlying health conditions arising from the systemic lack of disability-competent healthcare services mentioned above.

In fact, according to the U.S. Centers for Disease Control (CDC), adults with disabilities are three times more likely than the general population to have heart disease, stroke, diabetes or cancer. Yet we were months into the pandemic before the CDC added a single question related to disability to its COVID-19 case report form.

To ignore disability in data collection and research is to ignore a factor that amplifies all of the other risks arising from social disparities. Without a systemic shift and commitment to collect and report essential data on this population, it will continue to be impossible to appropriately allocate resources or implement strategies that address the needs of the millions of Americans living with a physical disability today and in the future.

*Regina Martinez-Estela is Co-President of Independence Care System (ICS), the first and only health home program designated as disability expert by the state of New York. For more than 20 years, ICS has helped thousands of New Yorkers with physical disabilities remain independent, at home, in their communities.*