The Issue: Health Inequity for People with Intellectual Disabilities in the COVID-19 Era

People with intellectual disabilities (ID) may be particularly vulnerable to infection with and complications from COVID-19. Young people and adults aged 18 to 74 with intellectual and developmental disabilities (IDD) die of COVID-19 at twice the rate of their counterparts without IDD.

To start with, many people with ID may be at increased risk of getting COVID-19. They have additional care and support needs that mean they are more likely live in group settings, like group homes or nursing homes, or to have an aide who travels to provide care. Indeed, around one-fifth of COVID deaths in the US as of April 2020 were tied to congregate settings, such as group homes, nursing homes, or institutions.

In one study, people with IDD died from influenza at nearly three times the rate of the general population; in another, respiratory illnesses were one of the primary causes of death for over 40% of the people with Down Syndrome whose deaths were studied.

Lack of training about and exposure to people with ID also means many health professionals feel uncomfortable treating them. Health professionals also may not know simple but important ways to adjust “business as usual” to effectively serve this patient population. Using simpler language and allowing a patient with ID to have their support person of choice present are examples of these crucial reasonable accommodations.

Difficulty accessing services is a significant reason that people with ID experience poorer health than the general population: people with ID have up to 2.5 times as many chronic health conditions as their peers in the general population.

There is much to learn about COVID-19, but studies have highlighted some of the chronic conditions that are prevalent among people with ID as risk factors for COVID-19 complications. For example: people with ID have up to two times the prevalence of asthma of the general population and hypertension is almost 35% more prevalent among adults with cognitive limitations than adults who have no disability.

With COVID-19 stretching resources thin, health care providers are being called on to make exceptionally complex ethical decisions in a rapidly changing operational environment. Health care provider judgments based on unconscious biases about people with intellectual disabilities can keep an entire population from getting life-saving health care.

The Solution: You can help people with ID during the COVID-19 crisis ... and beyond. Special Olympics can show you how.

Prioritize inclusion in funding for COVID prevention, testing, and treatment. Designate people with ID as a priority population in order to facilitate access to COVID-19 testing, and support funding to improve the health of people with ID during the pandemic and beyond.

Make sure health care settings are accessible and accommodating to people with ID. Support people are key for health equity of people with ID. Provide clear guidance that people with ID be allowed to have the support person of their choice available to them during COVID-19 care, and be sure to prepare a patient with ID adequately before procedures and treatments.

Build health provider skills to improve equity and outcomes. Require immediate, wide-scale health care provider and direct support staff training on working with people with ID during the pandemic.

Construct a data set to understand the COVID experiences and outcomes of people with ID. The scant data on COVID-19 among people with ID exposes shortcomings in overall public health surveillance of this population. Ensure that detailed data about COVID-related health care—as well as denial of care or limited medical resources—for people with ID are gathered and made publicly available.