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**The Issue:**

**Health Inequity for People with Intellectual Disabilities**

**in the COVID-19 Era**

**Fact #1:** People with intellectual disabilities (ID) have a long history of exclusion and discrimination. Today, this makes them more vulnerable to COVID-19 infection and complications.

* **People with ID have a hard time accessing quality health care**. Many people with ID have a path for obtaining health insurance, which should make it easier for them to access care. However, over 80% of health care professionals have not received training on how to treat people with ID.[[1]](#endnote-1) As a result, they often have little understanding of how to communicate with people with ID and care for them. Health professionals may not know how to adjust their standard approach to work: how to communicate, how much time to spend with the patient to understand symptoms, like shortness of breath or how to prepare them for procedures like nasal swab testing. They also may not feel comfortable treating this population. Insured people with ID also find that crucial home- and community-based services (HCBS) remain out of their reach, due to long waitlists for Medicaid coverage of these services in most states—for people with intellectual and developmental disabilities, the national average wait time for HCBS exceeds five years.[[2]](#endnote-2)
* **Long-term sub-standard access to health care means that people with ID are in worse health than the general population.** Certain conditions associated with intellectual disability have inherent health risks; for example, people with Down syndrome may have compromised immune systems, which lead to higher rates of respiratory illnesses, and people with cerebral palsy often have associated scoliosis or spine curvature and low muscle tone that produce higher risk of pneumonia and difficulties with secretions. [[3]](#endnote-3) However, difficulty accessing services is a significant contributor to the poor health status of people with ID: this population has more chronic health conditions than the general population, up to 2.5 times the number of health conditions as their peers in the general population.[[4]](#endnote-4) There is much to learn about COVID-19, but studies have highlighted some of the prevalent chronic conditions as risk factors for COVID-19 complications:[[5]](#endnote-5)
  + *Asthma***:** People with ID have significantly higher rates of asthma than the general population, up to two times the prevalence, and have higher rates of respiratory infection and fatality due to asthma. [[6]](#endnote-6)
  + *Diabetes*: Roughly 30% of overweight people have type 2 diabetes.[[7]](#endnote-7) Approximately half of adult Special Olympics athletes in the US are obese, compared to an estimated 42% of adults in the general population.[[8]](#endnote-8)
  + *Hypertension*: Adults with disabilities in the US are 13% more likely to have high blood pressure than adults without disabilities; 36.4% of adults with cognitive limitations have high blood pressure, versus 26.9% of adults with no disability.[[9]](#endnote-9)
* **Group care makes social distancing impossible.** Around one-third of people with ID continue to reside in congregate settings, such as group homes or institutions.[[10]](#endnote-10) Even people with ID who reside in the community often spend significant time in group settings such as adult day centers. The difficulty of social distancing in these settings because of the number of residents/participants and their care/support needs increases the risk of spreading COVID-19 infection. Numerous clusters of community COVID-19 transmission have centered on group care settings like nursing homes and group homes.[[11]](#endnote-11)
* **Family care presents its own challenges and risks.** Many adults with ID live with and receive care from older adults.[[12]](#endnote-12) Strict preventive social distancing by the household or older caregiver may pose challenges to the person with ID having all of their needs met—a situation that is significantly more dire if the caregiver contracts COVID-19 and then requires care in the home or is removed from the home. In addition, people with ID, like women and children without ID, may be at higher risk of experiencing violence at home during these times of high stress.[[13]](#endnote-13)

**Fact #2:** The COVID-19 pandemic is stretching resources, including medical equipment, provider time, and legal oversight, thin. People with intellectual disabilities are at risk of being de-prioritized for COVID-19-related medical attention, including life-saving measures, because of the medical community’s documented history of undervaluing the lives of these individuals.[[14]](#endnote-14)

* Policies that de-prioritize or disqualify people with ID for limited resources *solely on the basis of their disability* are plainly discriminatory, violate legal norms including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA), and must not stand.
* Many tools for allocating resources appear neutral but are actually discriminatory; for example, quality of life measures include assumptions about the lives of people with ID, and therefore should not be used.[[15]](#endnote-15)
* Health care providers are being called on to make exceptionally complex ethical decisions in a rapidly changing operational environment. Unconscious biases tend to come to the fore in these scenarios.[[16]](#endnote-16) Nevertheless, individualized assessments based on the best available medical evidence, combined with anti-discrimination/unconscious bias training and a high degree transparency about resource allocation policies and decisions, provide the best attainable balance.[[17]](#endnote-17)
* A person’s health status today depends on the access to health education and care they have received during their life until this point. This puts those who have a history of being left out most at risk of losing out on life-saving healthcare.

**Fact #3:** The lives of people with ID are valuable and worth saving.

* People with ID are beloved family members—[children to their parents](https://www.jointherevolution.org/50-game-changers/rajah), [often parents themselves](https://www.jointherevolution.org/50-game-changers/ricardo-thornton), many people with ID have romantic partners and siblings who love and cherish them.
* People with ID are [loyal and hard-working employees](https://www.jointherevolution.org/50-game-changers/pizzability), [creative contributors](https://www.jointherevolution.org/50-game-changers/la-casa-de-carlota), [treasured friends](https://www.jointherevolution.org/50-game-changers/rodney-hankins-and-sam-perkins), [fierce advocates](https://www.jointherevolution.org/50-game-changers/kester-edwards), and [accomplished athletes](https://www.jointherevolution.org/50-game-changers/jonny-pierce).

**Fact #4:** You can help people with ID during the COVID-19 crisis…and beyond. Special Olympics can show you how.

* + **An ounce of prevention is worth a pound of cure.** Designate people with ID as a priority population for COVID-19 testing in order to facilitate access to testing.
  + **Accessibility and reasonable accommodations mean different things to different people.** Provide clear guidance that people with ID be allowed to have the support person of their choice available to them during COVID-19 care.
  + **Information is power.** Require immediate, wide-scale health care provider and direct support staff training on working with people with ID during the pandemic.
  + **Let the sun shine in.** Ensure public availability of detailed data about the health care during COVID-19, including the allocation of limited medical resources.
  + **Be a champion of inclusion.** Support funding to improve the health of people with ID during the pandemic and beyond.

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