

Bias in the Health Care System

Advocating for People with Down Syndrome

LuMind IDSC Webinar October 19, 2022

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Adult Down Syndrome Center

Park Ridge, IL



Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.

Disclaimer

This information is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.

Objectives

- Discuss bias in health care
- Define ableism
- Share clinical examples
- Discuss strategies to address bias

Bias in Health Care

COVID-19

- States and hospitals established Crisis Standards of Care, Triage Guidelines, and No Visitor policies that discriminated against people with disabilities

Response from DS Organizations



8. Advocacy Matters

A. Hospital Visitation and Access to Care

- Due to the early spread of the virus, many hospitals created strict rules that hospitalized patients could not have many visitors. This policy was meant to save lives and reduce further spread of COVID-19. However, as of June 2020, [federal law requires](#) that hospitals modify policies to allow people with disabilities to have access to support from a parent or caregiver if needed while in the hospital.³⁵ Under the new federal hospital accommodation law, hospitals and other health care facilities are required to allow designated individuals (family members, staff, or others) to support any patient that may need such support and to provide personal protective equipment to these individuals.
- If you feel your child or adult with Down syndrome is experiencing discriminatory care, please contact any of the organizations listed on this document or contact the relevant national organizations involved in this issue, including:
 - » [The Arc](#)
 - » [Center for Public Representation](#)
 - » [National Disability Rights Network](#)
 - » [Office of Civil Rights](#)



Press Release

COVID-19 AND PRESERVING HUMAN RIGHTS FOR PEOPLE WITH DOWN SYNDROME

March 26, 2020

As medical systems plan for a possible flood of COVID-19 cases, the United States may draft guidance to ration care in order to manage the pandemic. However, LuMind IDSC has read reports that the guidance could limit access to needed services for people with Down syndrome, in violation of non-discrimination laws. LuMind IDSC and Public Representation, recently filed complaints with the U.S. Office for Civil Rights (OCR) (see links below).



Organizations representing individuals with disabilities, led by the Arc, recently filed a [complaint](#) with the U.S. Department of Health and Human Services Office for Civil Rights (OCR) highlighting the potential for widespread discrimination as health care professionals in the United States develop protocols for rationing life-saving treatment in response to possible COVID-19 resource scarcity. The complaint urges OCR to take [immediate action to investigate](#) such instances and to assist local jurisdictions and health care providers in developing non-discriminatory protocols that ensure access to life-saving treatments for people with disabilities.

March 30, 2020 by [NDSC](#)

[NDSC Statement on Discriminatory Medical Treatment Rationing During COVID-19 Crisis](#)

The National Down Syndrome Society (NDSS) supports the complaint to OCR and will work with you to protect the civil rights and equal access to healthcare for people with Down syndrome and other disabilities. To help us stay vigilant in this time of crisis, please let us know if you or someone you know with Down syndrome or another disability has been denied or withdrawn from health care services or equipment due to scarce COVID-19 resources.

If you have experienced discriminatory actions, please email Ashley Helsing, NDSS Director of Advocacy, at ahelsing@ndss.org.

Government Response

HHS Office for Civil Rights in Action



March 28, 2020

BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the [coronavirus disease 2019 \(COVID-19\)](#), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.¹

In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

"HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal," said Roger Severino, OCR Director. "Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism," Severino added.



April 10, 2020

Guidance Relating to Non-Discrimination in Medical Treatment for Novel Coronavirus 2019 (COVID-19)

During a pandemic such as COVID-19, healthcare providers are required to make difficult decisions concerning the allocation and rationing of limited healthcare resources, including staff, supplies, and space. As healthcare resources become scarce, hospitals and other healthcare institutions move through the continuum of care from conventional care, to contingency care, to crisis care. This guidance seeks to remind the healthcare community of their ongoing obligations to render healthcare in an ethical and non-discriminatory manner, obligations that are even more critical when providers are operating beyond their capacity. Healthcare institutions and providers must ensure effective protocols are in place in order to support the delivery of ethical, non-discriminatory decisions, especially those related to the allocation and rationing of limited healthcare resources.

It is essential that healthcare institutions operate within an ethical framework and consistent with civil rights laws that prohibit discrimination in the delivery of healthcare. Specifically, in allocating healthcare resources or services during public health emergencies, healthcare institutions are prohibited from using factors including, but not limited to race, ethnicity, sex, gender identity, national origin, sexual orientation, religious affiliation, age, and disability. Assumptions or stereotypes based on these characteristics serve no meaningful purpose in differentiating between people in the context of healthcare allocation decisions, and as further detailed below, are unacceptable both from an ethical standpoint, and as a matter of civil rights law.

Significant legal protections are in place to prohibit discrimination in the delivery of healthcare. Healthcare providers in the United States are subject to nondiscrimination mandates. Specifically, federal civil rights laws, including Section 1557 of the Affordable Care Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act, prohibit discrimination in the context of allocation of medical care. In addition to protections under federal law, the Illinois Human Rights Act provides that every person is entitled access to the "full and equal enjoyment of services." These laws provide a mandate to healthcare providers at all times, including during the current COVID-19 crisis.

Healthcare institutions should review their protocols regarding allocation and rationing of limited healthcare resources to ensure that they incorporate the fundamental principles of fairness, equity, and non-discrimination. This guidance provides recommendations for the delivery of appropriate care both during the immediate public health crisis caused by COVID-19 as well as to address the continued impact of the crisis on the healthcare system.

Health Care is at the Bedside,
not in Washington, D.C.

Impact of COVID-19

- In 2020, the first year of the pandemic, before vaccine availability:
- For those with intellectual disabilities, cerebral palsy, or Down syndrome, COVID-19 was the leading cause of death.

Original Article

COVID-19 mortality burden and comorbidity patterns among decedents with and without intellectual and developmental disability in the US

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ARTICLE INFO

Article history:
Received 6 June 2022
Received in revised form
26 August 2022
Accepted 30 August 2022

Keywords:
COVID-19
Mortality burden
Cause of death
Death certificates
Postmortem diagnostic overshadowing

ABSTRACT

Background: While there is ample evidence of increased COVID-19 mortality risk among people with intellectual and developmental disability (IDD), research has not documented whether this higher risk resulted in increased COVID-19 mortality burden in the US or whether comorbidity patterns among COVID-19 deaths are similar or distinct for people with IDD.

Objective: To determine the differences in COVID-19 mortality burden between decedents with and without IDD during the first year of the pandemic.

Methods: This study uses 2020 US death certificate data to compare COVID-19 mortality burden and comorbidity patterns among decedents with and without IDD.

Results: COVID-19 was the leading cause of death among decedents with IDD in 2020, compared with the 3rd leading cause among decedents without IDD. The proportion of deaths from COVID-19 was also higher for decedents with compared to without IDD. Comorbidities resulting from COVID-19 were similar among decedents with and without IDD, but there were some differences among reported pre-existing conditions, notably higher rates of hypothyroidism and seizures among decedents with IDD.

Conclusion: The COVID-19 mortality burden was greater for people with than without IDD during the first year of the pandemic. The continued practice of postmortem diagnostic overshadowing prevents analyzing whether this difference continues through today. Action is needed by the Centers for Disease Control and Prevention to mitigate this data inequity. Out of an abundance of caution, medical providers should carefully monitor symptoms among COVID-19 patients with IDD diagnosed with hypothyroidism and/or seizures.

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A recently published science brief by the Centers for Disease Control and Prevention (CDC)¹ summarizes evidence through May 2021 from multiple countries demonstrating more severe COVID-19 case and mortality risk among people with intellectual and developmental disabilities compared to the general population. Intellectual and developmental disabilities (IDD) such as intellectual disability, cerebral palsy, and Down syndrome are conditions that occur during the developmental period and are characterized by life-long impairments in mobility, language, learning, self-care, and independent living.² Increased COVID-19 mortality risk among people with IDD has been confirmed across various geographic

contexts and sample types: population based studies in Scotland³ and Ontario⁴; hospitalized COVID-19 patients in the UK⁵; health care organization data from the US⁶; data from IDD services providers^{7,8} and states^{9,10} in the US; and COVID-19 patients in an international sample of health care data.¹¹ While many of these studies do not differentiate by specific intellectual or developmental disability status, a few do, reporting higher rates of COVID-19 mortality among people with Down syndrome^{4,5,12} and cerebral palsy^{12,13} compared to the general population.

Studies in the general population indicate older age and pre-existing health conditions as risk factors for more severe COVID-19 outcomes.¹⁴ Although evidence demonstrates that people with IDD on average die at younger ages than the general population,^{15,16} increased age has been confirmed as a predictor of COVID-19 mortality among adults with IDD in a population study⁸ as well

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<https://doi.org/10.1016/j.dhjo.2022.101376>
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Why higher rate of mortality?

- Residential living
- Reliance on caregivers
- Co-occurring health conditions
- Socioeconomic differences
- Poor preventive health care
- Immunodeficiency associated with DS
- Differences in care resulting from bias



Research Paper

Medical vulnerability of individuals with Down syndrome to severe COVID-19—data from the Trisomy 21 Research Society and the UK ISARIC4C survey

Anke Hüls^a, Alberto C.S. Costa^{a,b}, Mara Dierssen^{a,c,d,e}, R. Asaad Baksh^{f,g}, Stefania Bargagna^h, Nicole L. Baumlerⁱ, Ana Claudia Brandão^j, Angelo Carri^k, Maria Carmona-Iragui^{l,m}, Brian Allen Chicoineⁿ, Sujay Ghosh^o, Monica Lakhampaul^o, Coral Manso^p, Miguel-Angel Mayer^q, Maria del Carmen Ortega^r, Diego Real de Asua^s, Anne-Sophie Rebillat^t, Lauren Ashley Russell^u, Giuseppina Sgandurra^{v,w}, Diletta Valentini^x, Stephanie L. Sherman^{y,z}, Andre Strydom^{z,w,x,y}, on behalf of the T21RS COVID-19 Initiative

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ARTICLE INFO

Article History:
Received 14 December 2020
Revised 5 February 2021
Accepted 5 February 2021
Available online 22 February 2021

See page 111 for detail of "on behalf of the T21RS COVID-19 Initiative".
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ABSTRACT

Background: Health conditions, immune dysfunction, and premature-aging associated with trisomy 21 (Down syndrome, DS) may impact the clinical course of COVID-19.

Case example

- Janet, 60-year-old woman with Down syndrome and early Alzheimer's disease
- Admitted to the hospital in fall 2020 with COVID-19-associated pneumonia
- Family did not want a do-not-resuscitate (DNR) order (requested full-code remain in place)
- Condition worsened, transferred to ICU
- ICU team asked at least 4 times about Janet's code status/DNR order, even when she started to improve

Ableism at the bedside

- Individual level
 - E.g., Janet
- Structural level
 - E.g., Crisis Standards of Care/triage
- Ableism/disability bias
 - *"the belief that the quality of life or worth of a person with a disability (PWD) is inherently less than that of a nondisabled person"*

Ableism at the Bedside: People with Intellectual Disabilities and COVID-19

Caitlin Chicoine, MD, Erin E. Hickey, MD, Kristi L. Kirschner, MD, and Brian A. Chicoine, MD

People with intellectual and developmental disabilities have a higher risk of mortality from COVID-19 than the general population. Providers may assume that this is due to the burden of comorbidities for this population; however, the disparity in mortality persists even when controlling for comorbidities. We review the current policies and practices that may be contributing to this higher level of mortality. We contend that pervasive ableism among medical providers leads to a variation in the medical care options that are provided to people with intellectual disabilities and their families. Due to this bias, poor outcomes for people with intellectual disabilities may become a self-fulfilling prophecy. We make recommendations to address the modifiable factors that are contributing to the higher level of mortality for people with intellectual disabilities who are infected with COVID-19, provide strategies to combat ableism within the medical field, and discuss the unique role of the primary care physician as an advocate. (J Am Board Fam Med 2022;35:390–393.)

Keywords: Ableism, COVID-19, Down Syndrome, Intellectual Disability

Janet, a 60-year-old woman with Down syndrome (DS) and early Alzheimer's disease, was admitted to the hospital in the fall of 2020 with COVID-19-associated pneumonia. On the general medical unit, she received supportive treatment with oxygen, steroids, and remdesivir. She was fortunate to have her primary care physician (PCP), a family physician who also serves as director of a specialized clinic for adults with DS, as her inpatient attending. He discussed goals of care with Janet and her family (including her sister who serves as her legal guardian), clarifying what they would want if Janet's condition were to worsen suddenly. Would they want any limits on her treatment, such as a do-not-*

resuscitate (DNR) order? The PCP counseled that there was no definitive evidence that Janet would not benefit from intensive treatment, and they all agreed that Janet had a rich, full life. A full code status was maintained. Her condition worsened over the next 24 hours, and she was transferred to the intensive care unit (ICU). The ICU team, on assuming care, asked her PCP why she did not have a DNR order.

People with DS (and other intellectual/developmental disabilities, or IDD) are known to be one of the highest risk groups for COVID-19 infectivity and mortality. A large cross-sectional study found that "having an intellectual disability was the strongest independent risk factor other than age for Covid-19 mortality."¹ The reasons for this heightened risk are not clear but may include genetic factors (such as cardiac defects or immune dysregulation in DS), comorbid conditions (such as obesity and type 2 diabetes, which are more prevalent in individuals with IDD),^{2,3} and structural vulnerabilities, such as socioeconomic disadvantage, congregate living, and poor preventative

This article was externally peer reviewed. Drs. Hickey and Chicoine contributed equally to this article and are co-first authors. Submitted 9 September 2021; revised 2 November 2021; accepted 5 November 2021.

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Funding: No sources of funding.

Conflicting and competing interests: None.

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Physician perceptions

- Survey of 714 practicing physicians in the U.S.
 - 82.4% - reported that people with significant disability have worse quality of life than nondisabled people
 - 18.1% - strongly agreed that the health care system often treats patients with disability unfairly

DISABILITY

By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressleran, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu, and Eric G. Campbell

Physicians' Perceptions Of People With Disability And Their Health Care

ABSTRACT More than sixty-one million Americans have disabilities, and increasing evidence documents that they experience health care disparities. Although many factors likely contribute to these disparities, one little-studied but potential cause involves physicians' perceptions of people with disability. In our survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5 percent strongly agreed that they welcomed patients with disability into their practices, and 18.1 percent strongly agreed that the health care system often treats these patients unfairly. More than thirty years after the Americans with Disabilities Act of 1990 was enacted, these findings about physicians' perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could contribute to persistent health care disparities affecting people with disability.

Released in 2000, *Healthy People 2010* was the first of the decennial reports produced by the Department of Health and Human Services (HHS) delineating national public health priorities to identify people with disability as experiencing health care disparities, partially attributing these inequities to common misconceptions about this population.¹ During the past two decades increasing evidence has documented persistent disparities for people with disability, now including more than sixty-one million Americans—numbers that will grow in coming years with the aging population. Disparities exist in screening and preventive services,^{2,4} cancer diagnosis and treatment,^{5,6} reproductive and pregnancy care,^{7,8} communication with health care professionals,^{9,10} and satisfaction with care.¹¹ Many patient-level factors likely contribute to these disparities, such as patients'

complex underlying health conditions,¹² disadvantages in social determinants of health,^{13,14} and patients' preferences for care.^{15,16} Systems-level factors also contribute, including inadequate training of health care professionals,^{17,18} ineffective communication accommodations,^{19,20} physical access barriers,^{21,22} and inadequate knowledge among physicians about legal requirements to provide equitable care under the Americans with Disabilities Act (ADA) of 1990.^{23,24} Despite it being more than thirty years since the enactment of this landmark civil rights legislation for people with disability, this population continues to experience inequitable health care on many levels.

One concern that has received relatively little empirical attention is the attitudes of physicians and specifically whether physicians have implicit or explicit biased views of people with disability. Over centuries, societies have stigmatized peo-

DOI: 10.1377/hlthaff.2020.01452
HEALTH AFFAIRS
Vol. 39, No. 2 (2021) 287–306
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The People's Voice for Health
Foundation, Inc.

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Impact of COVID-19

COMMENTARY

The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States

Jonathan Gleason, MD, Wendy Ross, MD, Alexander Fossi, MPHc, Heather Blonsky, MAS, Jane Tobias, DNP, RN, MSN, CPNP-PC, Mary Stephens, MD

Vol. No. | March 5, 2021

DOI: 10.1056/CAT.21.0051

A cross-sectional study of 64,858,460 patients across 547 health care organizations reveals that having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. Screening for Covid-19, care coordination, and vaccination efforts should be intense within this population that is less able to consistently use masks and socially distance.

Individuals with intellectual disabilities have poor health outcomes.^{1,2} Life expectancy for this population and those with developmental disabilities is nearly 20 years below that of the general population, and mortality for those with intellectual disabilities is significantly higher across their lifespan.³ Increased mortality in those with intellectual disabilities is caused by a number of factors and the impact of each is not well explored; in some cases, the cause of their disability or complications associated with their disability (in particular, difficulties with aspiration) may contribute to higher risk of mortality.⁴ In other cases, socioeconomic factors, obstacles to receiving the full amount of health care to which they should be entitled, and obstacles to effective advocacy for this population may contribute to an inability to receive appropriate and effective health care, which in turn leads to increased morbidity and mortality.⁵

Several smaller studies have demonstrated the effects of the pandemic on those with intellectual disabilities. One report demonstrated a higher case fatality rate for individuals with intellectual disabilities in California (.055 compared with .019 among the general population).⁶ A similar study of New York State residents found that those with intellectual disabilities or developmental disabilities were at greater risk of mortality, with those in residential group homes at especially high risk owing largely to elevated case rates. In this study, the mortality of those with intellectual

- People with ID were more likely to be diagnosed with COVID-19
- If diagnosed with COVID-19:
 - More likely to be admitted to the hospital
 - NOT more likely to be admitted to the ICU
 - More likely to experience mortality

Strategies

System-level

- Increase health professional and staff awareness and education about lived experience of individuals with disabilities.
- Encourage dialogue about ableism in the health care system.
- Promote an inclusive, patient-centered care culture through hospital compliance with Section 504 and the ADA

Family and community

- Communicate with the inpatient team about patient's baseline cognitive, functional, and medical status *and* patient and family's values and perception of quality of life.
- Consider using other communication strategies (such as health passports) to provide critical medical and disability-specific information to new care providers.
- Ensure that persons with disabilities have a seat at the table (involvement in hospital policy discussions, ethics committees, and health care workforce).

Family and community

- Stay with the individual while they are in the hospital.
- Share resources with care providers.
- Personalize.

"I realized my real hopes for Josephine are that she feels loved ... and that she feels valued and respected... I realized that none of those things are dependent on specific abilities or disabilities. They are dependent on who she is as a person, and how we treat her as a person."

-K. Jane Lee, MD. *Catastrophic Rupture: A Memoir of Healing*, pg. 162

Start Young



Different is OK!

Conclusion

- Progress is being made but there is still work to be done.



myDSC Webinar SERIES

Bias in the Health Care System:
Advocating for People
with Down Syndrome



Presented by:
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October 19, 2022
1 PM ET / 12 PM CT / 10 AM PT

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