

Can Virtual Care Improve the Lives of Individuals with Intellectual Disabilities?

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NEJM
Catalyst | Innovations in Care Delivery

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.



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Organization alleges vaccine discrimination

Brandon Glass bglass@tin  Mar 10, 2021

Maryland's Executive Order and Vaccination Plan does specify that developmentally disabled populations are to be vaccinated in Phase 1B of the plan.

The lawsuit also named Carroll, Queen Anne's, Somerset and Talbot counties.

According to the New England Journal of Medicine, studies have found that fatality rates are two to three times greater among people with intellectually and developmental disabilities who test positive for COVID-19 than the general population.



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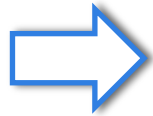
The Philadelphia Inquirer

Opinion



Intellectual disability is the top unspoken risk factor for COVID-19. So why is it not prioritized for vaccine? | Opinion

When confronted with this sobering data, nothing has changed in the CDC recommendations for vaccination. Unfortunately, this conscious and unconscious bias has long infiltrated medicine.



March 11, 2021



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▶ WATCH LIVE

Philadelphia Pennsylvania New Jersey Delaware

Philadelphia expands phase 1B qualifications for COVID-19 vaccine



Friday, March 19, 2021

PHILADELPHIA (WPVI) -- Philadelphia's health commissioner announced a small expansion for COVID-19 vaccine eligibility group 1B during a news conference on Friday morning.

Dr. Thomas Farley said the high-risk category now includes people with intellectual disabilities and an expansion of the definition of immunosuppression to include those taking medicine to suppress the immune system "for any cause."



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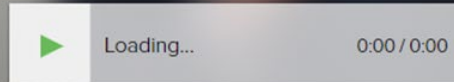
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Kentucky Changes Its Vaccine Policy After Questions About Prioritizing People With Disabilities



Photo: Courtesy Nathan French

By Corinne Boyer



CORONAVIRUS HEALTH March 19, 2021



UPDATE: After this story was published, Kentucky Gov. Andy Beshear addressed the vaccine status for people with intellectual and developmental disabilities during his coronavirus briefing on Monday, March 22.



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Search

Japan to prioritize those with severe mental illness, intellectual disabilities for vaccine

March 19, 2021 (Mainichi Japan)

Japanese version



The building housing the Ministry of Health, Labor and Welfare is seen in Tokyo's Chiyoda Ward. (Mainichi/Kimi Takeuchi)

TOKYO -- In addition to a group of people with underlying conditions, individuals with severe mental illness or intellectual disabilities will be among those who will be given priority in receiving the coronavirus vaccination following elderly people aged 65 and older, the Ministry of Health, Labor and Welfare decided on March 18.



Timeline



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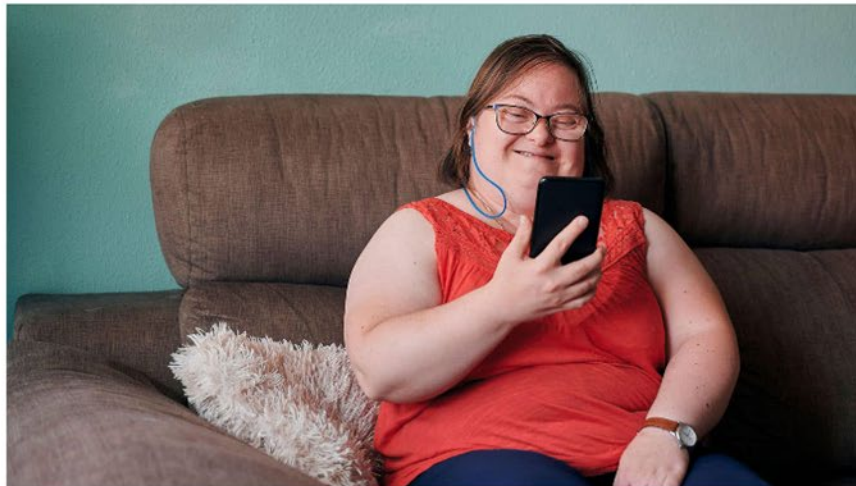
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Opinion > Second Opinions

Prioritize People With Intellectual Disabilities for COVID Treatment

— This at-risk group has not received adequate attention

by Wendy Ross, MD, and Jonathan Gleason, MD January 10, 2022



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COVID-19



Your Health

Vaccines

Cases & Data

Work & School

Healthcare Workers

Health Depts

Science

More

People with Certain Medical Conditions

Updated Feb. 25, 2022 Languages Print

Disabilities

People with some types of disabilities may be more likely to get very sick from COVID-19 because of underlying medical conditions, living in congregate settings, or systemic health and social inequities, including:

- [People with any type of disability that makes it more difficult to do certain activities or interact with the world around them, including people who need help with self-care or daily activities](#)
- [People with attention-deficit/hyperactivity disorder \(ADHD\)](#)
- [People with cerebral palsy](#)
- [People with birth defects](#)
- [People with intellectual and developmental disabilities](#)
- [People with learning disabilities](#)
- [People with spinal cord injuries](#)
- [People with Down syndrome](#)



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COVID-19 Was the Leading Cause of Death...

Disability and Health Journal 15 (2022) 101376

Contents lists available at ScienceDirect

 **Disability and Health Journal**

journal homepage: www.disabilityandhealthjnl.com

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

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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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Intellectual and Developmental Disability

- **Definition:** Cognitive and functional limitations
- **Prevalence:** 1-3%—200 million worldwide
- **Health Outcomes:** Fewer years
- **Cost:** High

Published in final edited form as:

J Pediatr. 2021 February ; 229: 259–266. doi:10.1016/j.jpeds.2020.08.084.

Disability, Hospital Care, and Cost: Utilization of Emergency and Inpatient Care by a Cohort of Children with Intellectual and Developmental Disabilities

Scott Lindgren, PhD¹, Emily Lauer, MPH², Elizabeth Momany, PhD³, Tara Cope, MS⁴, Julie Royer, MSPH⁵, Lindsay Cogan, PhD⁶, Suzanne McDermott, PhD⁷, Brian S. Armour, PhD⁸

1. Lee C. Combined Federal and State Spending on Medicaid Home and Community-Based Services (HCBS) Totaled \$116 billion in FY 2020, Serving Millions of Elderly Adults and People with Disabilities. Kaiser Family Foundation. March 4, 2022. Accessed April 27, 2022. <https://www.kff.org/medicaid/press-release/combined-federal-and-state-spending-on-medicaid-home-and-community-based-services-hcbs-totaled-116-billion-in-fy-2020-serving-millions-of-elderly-adults-and-people-with-disabilities/>.
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3. E Emerson, C Hatton, S Baines, J Robertson. The physical health of British adults with intellectual disability: cross sectional study. *Int J Equity Health* 2016; 15:11. doi:10.1186/s12939-016-0296-x.26791808.
4. MJ de Leeuw, A Oppewal, RG Elbers. Healthy Ageing and Intellectual Disability study: summary of findings and the protocol for the 10-year follow-up study. *BMJ Open* 2022; 12:e053499. doi:10.1136/bmjopen-2021-053499.35193910.



Caring for this population can be challenging!

- <https://www.specialolympics.org/stories/impact/10-tips-from-special-olympics-athletes-on-how-to-make-covid-19-vaccination-clinics-inclusive>

DR Patel, MD Cabral, A Ho, J Merrick. A clinical primer on intellectual disability. Transl Pediatr 2020; 9:Suppl 1:S23-S35 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7082244/>. 10.21037/tp.2020.02.02.32206581.



Benefits of Telehealth for IDD Patients

- Removes sensory barriers
- Removes barriers of caregivers that work outside of the home
- Removes travel barriers and costs
- Incorporates other professionals on team even if they are in different locations
- May be more accessible than in person meetings—ie some people with IDD find tech MORE accessible than in person interactions
- Increase **frequency** of monitoring
- May extend the limited resource of clinicians that treat IDD.



What is the Evidence?

Review Article

Virtual health care for adult patients with intellectual and developmental disabilities: A scoping review

Avra Selick, MA, PhD(c)^{a, b, *}, Nicole Bobbette, PhD^{b, c}, Yona Lunsky, PhD^{a, b},
Yani Hamdani, PhD^{a, b}, Jennifer Rayner, PhD^a, Janet Durbin, PhD^{a, b}

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^c Queen's University, 99 University Ave, Kingston, ON, K7L 3N6, Canada

Discussion

The aim of this scoping review was to examine what is known about delivering virtual health care to adults with IDD. Most of the research on virtual care and people with IDD has focused on children and only 22 studies were identified that included adults. Most of these 22 studies focused on services delivered by specialists in the field of IDD; fewer studies focused on services provided by mainstream health care providers. In many cases participants received care from a clinic where a trained staff member was present to facilitate the virtual interaction. This limits the applicability of findings to the current experience during the pandemic where patients and caregivers are accessing health care services from home. Most of the included studies were small trials or pilot studies, almost half of which had fewer than 30 participants.



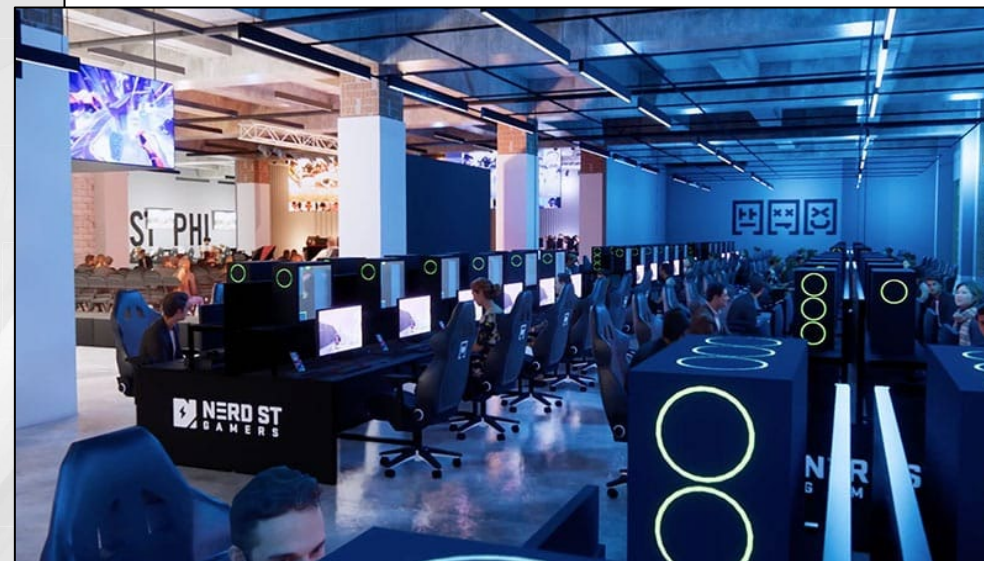
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Let's start by challenging our assumptions...



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High Satisfaction for Telehealth for IDD...

Journal of Autism and Developmental Disorders (2022) 52:5253–5265
<https://doi.org/10.1007/s10803-022-05712-x>

BRIEF REPORT



Brief Report: Telehealth Satisfaction Among Caregivers of Pediatric and Adult Psychology and Psychiatry Patients with Intellectual and Developmental Disability in the Wake of Covid-19

Victoria Rosen¹ · Elizabeth Blank¹ · Erica Lampert² · Kelli Dominick^{1,3} · Meredith Will¹ · Craig Erickson^{1,3} · Ernest Pedapati^{1,3} · Martine Lamy^{1,3} · Rebecca Shaffer^{1,3}

Accepted: 3 August 2022 / Published online: 20 August 2022

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Abstract

Telehealth has been shown to be both acceptable and effective in many areas of healthcare, yet it was not widely adopted prior to the SARS-CoV-2 (COVID-19) pandemic. Additionally, previous evaluations of telehealth for autism spectrum disorder (ASD) and intellectual and developmental disability (IDD) populations are limited in both number and scope. Here, we investigated satisfaction amongst Psychology and Psychiatry patient caregivers at Cincinnati Children’s Hospital Medical Center (CCHMC) after the onset of the COVID-19 pandemic. Results (640 responses) showed high rates of satisfaction across departments, appointment types, and diagnoses, with 92% indicating overall satisfaction with their appointment. There were, however, notable decreases in satisfaction among Group Therapy respondents, and those whose diagnosis was classified as Other.

5258

Journal of Autism and Developmental Disorders (2022) 52:5253–5265

Table 3 Satisfaction overall, by department, and by appointment type

| Survey question | Satisfaction criteria | All % (n of N) | Departments | | Appointment types | | | | |
|--|-------------------------|------------------|-----------------------|-----------------------|-----------------------------|-----------------------------|--------------------------|----------------------------------|------------------|
| | | | Psychology % (n of N) | Psychology % (n of N) | Psych Evaluation % (n of N) | Behavior therapy % (n of N) | Group therapy % (n of N) | Medication management % (n of N) | Other % (n of N) |
| (3) Overall, I am satisfied with my telehealth appointment | Agree or strongly agree | 92% (590 of 638) | 93% (224 of 242) | 92% (366 of 396) | 91% (10 of 1177) | 94% (194 of 206) | 79% (23 of 29) | 93% (236 of 253) | 93% (14 of 15) |



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Considerations of Telehealth for IDD

- Ensure that the tech is accessible
- Ensure that caregivers are included as appropriate
- Ensuring patients are seen in person when needed or appropriate (ie should not be to avoid physical examinations when needed)



Applications of Telehealth to IDD

- Direct healthcare
- Remote patient monitoring and chronic care management
- Adjunct to home nursing and monitoring
- Multidisciplinary team meetings (pediatrician, psychologist, therapist, social work, caregiver).



Additional Applications to Improve Quality of Life

- Expanding activities of daily living
- Expanding skills
- Expanding opportunities for physical fitness
- Providing community
- Increasing opportunities for education
- Increasing access to employment
- Virtual reality to expand or explore experiences and to practice



Telehealth Won't Solve the Bias Problem...

DISABILITY

By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressler, 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

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Sowmya R. Rao is a statistician in the Biostatistics Center at

The New York Times

These Doctors Admit They Don't Want Patients With Disabilities

When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.

Give this article | 1.2K



EXHIBIT 2

Bivariable associations between perceptions about people with disability (PWD) and their care and survey participant characteristics

| | Strongly agree that understanding PWD is valuable to them as physician | | Strongly agree that PWD are treated unfairly in health system | | Rates quality of life for PWD as worse | | Very confident about providing same quality of care for PWD | |
|------------------|--|------|---|------|--|------|---|------|
| | No. | % | No. | % | No. | % | No. | % |
| All participants | 544 | 79.8 | 116 | 18.1 | 569 | 82.4 | 283 | 40.7 |

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Telehealth May Be the Future for IDD...

- Additional Studies are Needed.
- Virtual-first care models should be explored.
- Virtual care should be covered by insurance for IDD.



Questions?

