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Contents lists available at ScienceDirect

# Disability and Health Journal

journal homepage: [www.disabilityandhealthjnl.com](http://www.disabilityandhealthjnl.com)

## Editorial

### People with disability and the COVID-19 pandemic: The need for empiric research



The COVID-19 pandemic continues to overshadow public health, health care, health policy, and related research efforts. In general, biomedical journals have supported the expedited peer-review and publication of manuscripts to better define the issues surrounding the SARS-CoV-2 virus, including the virus itself and its expected mutations, risks, prevention strategies, treatments, outcomes, vaccination, and future projections. While research, public health, and medical communities have gained insights into many of these topics, there continues to be limited data driven information for public policy and health leaders to use in developing prevention and treatment guidance for people with disabilities and their caregivers.

The *Disability and Health Journal* (DHJO) has published several articles focused on people with long term disability conditions, reporting on their risks for becoming infected, their outcomes from the infection, the consequences of the lockdown, and their experiences throughout the pandemic. We have primarily sought manuscripts focused on empirical research, recognizing the need for data and evidence to guide the development of equitable policies for people with disability and their caregivers. However, there continues to be a paucity of articles that use data to clearly define the issues of people with disability and the SARS-CoV-2 virus, compared to the general population.

DHJO has now published 16 articles related to the pandemic and people with disability – there are seven articles in this issue. Once an article is accepted, the pre-print is immediately posted to the DHJO website; all pandemic-related articles are deemed Open Access by Elsevier. Ten (63%) of the articles are empirical research, with a few having contributed to U.S. national policy. As a comparison, we completed a quick search for the first 50 publications in PubMed and Google Scholar using “disability and COVID-19” as a search phrase. Within PubMed, 48% (n = 24) of articles were empiric, with just over half being commentaries, opinions, or overviews of experiences of clinicians or patients. Interestingly, 34% (n = 17) of these articles were related to new onset disability from COVID-19, and 12 of those (70% of new onset articles) contributed to the empiric articles (50% of empiric articles). There was a similar result in Google Scholar, showing only 24% (n = 12) of articles reporting empirical research results. While rigorous methodology was not implemented in our search, the overwhelming presence of commentary and opinion articles is disappointing. Commentaries, opinion articles and personal accounts can be very powerful, but underlying research provides reproducible evidence to move health care and policy decisions.

One obvious limitation is the lack of reliable reported data. Gender and race/ethnicity were not required for report of cases and fatalities early in the pandemic, but now are. Disability status

has never been required for any surveillance reporting. Researchers have found databases conducive to identifying disability conditions and cases/fatalities, used secondary data analysis, partnered with advocacy and other organizations collecting data, and developed surveys hoping for broad representation of people with disability. There is a growing body of literature that has been helpful in identifying disparities and developing health policy, but there remains an obvious lag in peer-reviewed publications.

The latest concern related to people with disability and the pandemic is access to the vaccine. People with disability are largely missing from priority listing to receive the vaccine in many states. Those in congregate settings (e.g., nursing homes, intermediate care facilities, group homes) have been acknowledged in some state priority plans, but not people with disability living in their own or family's home, with or without in-home services. Centers for Disease Control and Prevention has noted people with Down Syndrome as being at high risk for severe illness (<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>), citing strong supporting evidence. However, people with a variety of disability conditions do experience many of the “strong evidence” comorbid conditions (<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/evidence-table.html>), which would put them at risk for severe illness should they become infected. Some states have taken higher risk conditions into consideration, but not all.

It continues to be the goal of DHJO to promote empiric research articles related to the needs and outcomes of people with disability. While commentaries and opinion pieces can identify areas of concern, it appears that data driven articles are much needed to support the health interests of people with disability in health policy. We welcome further submissions!

We also want to take this opportunity to acknowledge the passing of Dr. Margaret Nosek, a founding member of the *Disability and Health Journal* Editorial Board. Dr. Nosek, an activist in the disability rights and independent living movement, was a pioneering disability and health researcher and scholar. Her formative research on the health and well-being of women with disabilities made ground-breaking contributions to disability and health research. We are grateful for her leadership, scholarship, and activism in advancing disability rights and research.

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