
VOR -- Public Submission to the CDC ACIP (ACIP) Meeting, February 22-24, 2023
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VOR – A Voice Of Reason – a more than 40-year-old national non-profit organization, advocates for high-quality care and human rights for all people with intellectual and developmental disabilities (I/DD) and autism. VOR primarily represents individuals with the most severe degrees of I/DD and autism, and their families and guardians. The needs of individuals at this end of the I/DD spectrum are existential: While they become physically full-grown, age-wise, they typically function at the intellectual level of infancy to the toddler years. Most also have significant complicating physical or psychiatric/behavioral issues or both.

As a whole, this cohort of disabled individuals is at elevated risk for both COVID-19 infection and poor outcomes. Indeed, many of them are at extremely high risk. This has been demonstrated by published research, and has been incorporated into CDC guidance regarding COVID-19.

The ACIP’s 2023 recently approved and published Recommended Adult Immunization Schedule’s section on *COVID-19 vaccination* -- including recommendations for persons who are moderately or severely immunocompromised and hyperlinks referring health care providers to booster dose recommendations and to use of COVID-19 preexposure prophylaxis in persons who are moderately or severely immunocompromised -- is a welcome and badly-needed addition to the limited armamentarium available to protect these most vulnerable individuals.

At the same time, the real-world circumstances facing the most vulnerable of them make clear that these new recommendations, which explicitly target only narrowly-defined moderate-to-severe immune-compromise conditions, will not lend enough protection to the cohort of individuals whom we represent:

A recent *Disability and Health Journal* study of all 2020 U.S. death certificates found that COVID-19 was the leading cause of death among decedents with I/DD that year. It also found that postmortem diagnostic overshadowing – the inaccurate reporting of intellectual and developmental disabilities on death certificates, a then-current data inequity that permitted I/DD to be reported as the cause of death – is likely still prevalent two years later, such that COVID-19’s toll on this population might be even higher than thus far identified.¹

¹ COVID-19 Mortality Burden and Comorbidity Patterns among Decedents with and without Intellectual and Developmental Disability in the US, Scott D. Landes PhD, Julia M. Finan BA, and Margaret A. Turk MD, *Disability and Health Journal*, Volume 15, Issue 4, October, 2022: <https://doi.org/10.1016/j.dhjo.2022.101376> ; also:

A Call To Eliminate Postmortem Diagnostic Overshadowing For People With Intellectual And Developmental Disabilities, Scott D. Landes PhD, and Margaret A. Turk MD, *Health Affairs Forefront*, April 19, 2022: <https://www.healthaffairs.org/doi/10.1377/forefront.20220418.766115>

And a recent analysis in *Health Affairs* showed that, in the pandemic's first 10 months, people in Medicaid Home and Community Based Service (HCBS) programs, comprising a great many people with I/DD and physical disabilities, experienced more excess mortality than did even Medicaid's nursing home residents – for those age 65 and under, 35 percent excess mortality vs. 11 percent excess mortality; and for those over age 65, 31 percent vs. 28 percent. Excess mortality for 65-and-under HCBS participants, compared to 65-and-under Medicaid recipients not in HCBS, was also shockingly elevated: 35 percent vs. 22 percent.²

Per the CDC, with respect to underlying medical conditions, “disabilities, including Down syndrome” are, conclusively, in the highest-risk category for severe COVID-19 outcome.³

A recent case in our I/DD community captures this current reality: A female adult in her 50s with Down syndrome, related lifelong profound intellectual disability and dementia, who had previously been multiply-vaccinated against COVID-19, was, upon COVID-19 diagnosis, prescribed Paxlovid while still an outpatient with only minor symptoms. But she could not ingest the large, uncrushable pills because of impaired swallowing. A few days thereafter, she experienced significant respiratory distress, and only upon hospitalization could receive remdesivir (as well as, of course, considerable other lifesaving support). Preexposure prophylaxis was nonexistent. Likewise, possibility of monoclonal antibody support was nil, nor could her circumstance growing more dire change that sad fact. Fortunately, she survived.

VOR understands and appreciates that -- as the ACIP itself puts it – its developing recommendations and assisting providers on the use of vaccine for COVID-19 -- after in-depth review of disease burden, vaccine safety and efficacy, evidence quality, implementation feasibility, economic considerations, and so much more) -- is indeed “complex and challenging to implement.”

At the same time, **VOR urges the ACIP, as it goes forward ongoingly and dynamically updates its recommendations, to also maximally consider the needs of the I/DD and severe autism populations.** In frankness, their needs in this regard are, on average, far more pressing than those of the three age groups encompassing all those from ages 19 through 64. Nor are these vulnerable souls' dire risks and severe outcomes currently highlighted or accorded particular focus within the recommendations as are, for example (and deservedly so), those of “persons who are moderately or severely immunocompromised.”

The population for whom we advocate is likewise deserving of the highest-level attention with regard to the only substantive preventive there is for them from COVID-19. That is all we ask.

Thank you for your attention to VOR's concerns on behalf of individuals with I/DD and autism.

² Excess Deaths Of Medicaid Home And Community-Based Services Recipients During COVID-19, H. Stephen Kay and Joseph Caldwell, *Health Affairs*, Volume 42, No. 1, January, 2023: <https://doi.org/10.1377/hlthaff.2022.00457>

³ Underlying Medical Conditions Associated with Higher Risk for Severe COVID-19: Information for Healthcare Professionals, Centers for Disease Control, and Prevention website, Updated February 9, 2023 <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlyingconditions.html#complete-list-disabilities>