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# **Additional Advocacy Opportunities and Strategies**

**Note: State lobbying laws may contain provisions about the amount of time and level of lobbying that is permitted and must be reported to authorities. Each Special Olympics Program is responsible for ascertaining their own obligations under state law and must follow state lobbying laws when advocating.**

Many people with intellectual disabilities (ID) live in a long-term congregate care setting, such as a group home, jointly paid for with federal Medicaid and state funds. Because of the dual sources of funding, these facilities are subject to dual regulatory authority by the federal and state governments.

Regardless of their funding source, all entities must abide by federal non-discrimination legislation, including the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. State non-discrimination legislation may also apply.

Crisis Standards of Care are documents that detail the adjustments in medical care provision that must be made in certain disaster scenarios in order to manage the risk and mitigate the impacts. [[1]](#endnote-1) Around one-quarter of states do not have Crisis Standards of Care, which causes decentralized decision-making and can create opportunities for inequity within a state.

While around three-quarters of states have Crisis Standards of Care, many of them adopted the federal standards wholesale in the midst of the COVID-19 crisis.[[2]](#endnote-2) Not developed or tailored for the state’s needs, this practice may create difficulties for practical implementation on the ground. A number of states’ guidelines continue to reference specific conditions or impairments as factors to consider; those that do not often consider aspects that will still systematically disfavor people with ID, because of this population’s historical exclusion.[[3]](#endnote-3)

Finally, the Crisis Standards of Care issued by a number of states drew attention because of language that would seemingly restrict the care that certain groups of the population could receive in resource-limited conditions.[[4]](#endnote-4) The Department of Health and Human Services (HHS) Office of Civil Rights (OCR) reiterated the force and scope of federal non-discrimination legislation, even in the ongoing public health crisis. Its communication made clear that there can be legal repercussions for developing and applying discriminatory guidelines, and it has worked collaboratively with some states to bring their Standards into compliance with federal law. [[5]](#endnote-5)

## **Opportunities**

Against this backdrop, the following policy proposals would promote greater equity for people with intellectual disabilities:

1. The state health department and/or state regulatory authority for congregate care for people with ID should immediately facilitate universal COVID-19 testing for residents and staff of congregate care facilities.[[6]](#endnote-6)
2. The state health department and/or other authorities should designate people with ID as a priority population for COVID-19 testing in order to facilitate access to testing by people with ID living in the community who may be at greater risk of coronavirus infection; associated complications from infection, due to comorbidities present in this population; and contributing to community spread through contact with caregivers.
3. The state health department and/or state regulatory authority for congregate care for people with ID should require staff at congregate care facilities to receive training on particular vulnerability of people with ID to contracting COVID-19 and downstream effects, including associated complications at the individual level, spread at the home level, and contagion at community level driven by asymptomatic non-resident care staff.
4. The state health department and/or state regulatory authority for congregate care for people with ID should designate staff at congregate care facilities as priorities for the use of personal protective equipment (PPE).
5. The state health department and/or state regulatory authority for congregate care for people with ID should require the development of risk mitigation and response plans, including staff training on preventive measures, recognition of symptoms, and appropriate responses.
6. The state health department, state offices of civil rights, and/or other appropriate authorities should ensure that information on COVID-19 that is accessible to people with ID (plain language, use of graphics) and other disabilities (people who are deaf or blind) is developed and widely publicized and disseminated.
7. The state offices of civil rights and/or other appropriate authorities should issue guidance that people with ID must be allowed to have a support person of their choice with them during testing and COVID-19-related medical treatment as a reasonable modification in policy, practice, and procedure necessary to afford services to a person with ID required by the ADA.[[7]](#endnote-7)
8. Governors, state legislators, and others involved in the development of Crisis Standards of Care, which address the issue of medical rationing, should direct health care providers to reach these difficult decisions by making individualized assessments of the patients before them.
9. State health and social services agencies should develop clear protocols about how people with ID will receive care if their caregiver contracts coronavirus/COVID-19 and is hospitalized.
10. State health regulatory authorities should ensure that people with ID are able to have continuous access to any needed prescribed medication; for example, by authorizing early prescription refills or extended supplies of medication and ensuring insurance coverage for these modifications.[[8]](#endnote-8)

### **Strategies**

A few possible strategies for pursuing the advocacy opportunities outlined above are:

* Set up an online advocacy campaign that will allow your grassroots networks to very easily reach out to their state officials on behalf of Special Olympics – contact Meredith Pierce and Shawn Ferguson for support.
* Develop an advocacy-focused communications strategy – raise awareness of the health equity issues people with ID face using social or traditional media.
* **In cooperation with the SOI HQ Government Relations team**, invite your grassroots networks to place calls to federal officials on behalf of Special Olympics’ pending federal advocacy. **Please look out for notices and requests for action related to such opportunities** from Meredith Pierce and Shawn Ferguson.
* Develop or sign on to coalition letters to state officials or other stakeholders (see example) – **please refer to the included example only as an example and do not copy language from it, which was not developed by Special Olympics.**
* Share information about people with ID with state officials and other stakeholders.
* Collect and share stories about athletes’ experiences with the health system during the COVID-19 pandemic – please share these with SOI to spotlight in federal/national advocacy and communications.
* Work with local coalitions or a champion in your legislature to develop relevant legislation.



1. Institute of Medicine (US) Forum on Medical and Public Health Preparedness for Catastrophic Events. Crisis Standards of Care: Summary of a Workshop Series. Washington (DC): National Academies Press (US); 2010. Related IOM Work on Crisis Standards of Care. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK32749/> [↑](#endnote-ref-1)
2. Hawryluk, M. During A Pandemic, States’ Patchwork of Crisis Strategies Could Mean Uneven Care. *Kaiser Health News,* March 5, 2020*.* <https://khn.org/news/during-a-pandemic-states-patchwork-of-crisis-plans-could-mean-uneven-care/>. [↑](#endnote-ref-2)
3. Essley Whyte, L. State Policies May Send People with Disabilities to the Back of the Line for Ventilators. *The Center for Public Integrity*, April 8, 2020. <https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators/> [↑](#endnote-ref-3)
4. HHS-OCR Complains Re COVID-19 Medical Discrimination, March 23, 2020. <https://thearc.org/resource/hhs-ocr-complaint-of-disability-rights-washington-self-advocates-in-leadership-the-arc-of-the-united-states-and-ivanova-smith/>. [↑](#endnote-ref-4)
5. HHS Office for Civil Rights in Action. (2020). Bulleting: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), March 29, 2020. <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.HHS> Office for Civil Rights, OCR Reaches Early Case Resolution With Alabama After It Removes Discriminatory Ventilator Triaging Guidelines, April 8, 2020 <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html>. [↑](#endnote-ref-5)
6. These will include ICFs and HCBSs. The agency with regulatory authority will vary by state. [↑](#endnote-ref-6)
7. Institute of Medicine (US) Committee on Disability in America; Field MJ, Jette AM, editors. The Future of Disability in America. Washington (DC): National Academies Press (US); 2007. D, The Americans with Disabilities Act in a Health Care Context. <https://www.ncbi.nlm.nih.gov/books/NBK11429/>. [↑](#endnote-ref-7)
8. Cubanski, J., Schwartz, K. & Damico, A. (2020). *Examining Medicare Part D Policies for Extended Supplies of Medication.* Kaiser Family Foundation (KFF).<https://www.kff.org/medicare/issue-brief/examining-medicare-part-d-policies-for-extended-supplies-of-medication/>. McCook, A. (2020). *COVID-19: Stockpiling Refills May Strain the System.* Infectious Disease Special Edition (IDSE). <https://www.idse.net/Policy--Public-Health/Article/03-20/COVID-19-Stockpiling-Refills-May-Strain-the-System/57583>. This benefit has been offered to Medicare subscribers, as well as on a case-by-case basis by a number of private insurance companies, but benefit should be made available to all. [↑](#endnote-ref-8)