#

# **Additional Advocacy Opportunities and Strategies**

**Note: Your country may have laws, policies, and practices that govern if lobbying or other types of advocacy are permitted, what forms these can take, how much time a non-profit organization can spend on such activities, and if/how these activities must be reported to authorities. Each Special Olympics Program is responsible for ascertaining their own rights and obligations under their jurisdiction’s law and must follow local lobbying laws, policies, and practices when advocating.**

Many people with intellectual disabilities (ID) live in a long-term congregate care setting, such as group homes. Most countries in the world have signed or ratified the United Nations Convention on the Rights of Persons with Disabilities and most countries also have a non-discrimination law which often, but does not always, forbid discrimination on the basis of disability.

## Opportunities

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

1. The Ministry of Health, local (e.g., municipal) health department, and/or regulatory authority for congregate care for people with ID should immediately facilitate universal COVID-19 testing for residents and staff of congregate care facilities, including institutions.
2. The Ministry of Health, local (e.g., municipal) 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 Ministry of Health, local (e.g., municipal) health department, and/or regulatory authority for congregate care for people with ID, including institutions, 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 Ministry of Health, local (e.g., municipal) health department, and/or regulatory authority for congregate care for people with ID, including institutions, should designate staff at congregate care facilities as priorities for the use of personal protective equipment (PPE).
5. The Ministry of Health, local (e.g., municipal) health department, and/or regulatory authority for congregate care for people with ID, including institutions, should require the development of risk mitigation and response plans, including staff training on preventive measures, recognition of symptoms, and appropriate responses.
6. The Ministry of Health, Ministry of Justice, local (e.g., municipal) health department, human rights authorities, 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 Ministry of Health, Ministry of Justice, local (e.g., municipal) health department, human rights authorities, 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 accommodation necessary to ensure people with ID can enjoy their rights as required by the CRPD, where applicable.[[1]](#endnote-1)
8. Government officials 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. Health and social services agencies at all levels should develop clear protocols about how people with ID will receive care if their caregiver contracts coronavirus/COVID-19 and is hospitalized.
10. 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.[[2]](#endnote-2)

### Strategies

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

* Develop an advocacy-focused communications strategy – raise awareness of the health equity issues people with ID face using social or traditional media.
* Develop or sign on to coalition letters to key stakeholders (see example from the US) – **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 government 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 international advocacy and communications.
* Work with local coalitions or government champions to develop relevant legislation.



1. 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-1)
2. 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-2)