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*TOOLKIT:*  
**Health Advocacy for People with Intellectual Disabilities in the COVID-19 Pandemic**

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While every community in the United States is in a different position regarding the  
COVID-19 pandemic, Special Olympics Programs all have one thing in common: an interest in ensuring health equity for people with intellectual disabilities (ID).

# *TOOLKIT:* Health Advocacy for People with Intellectual Disabilities in the COVID-19 Pandemic

Acknowledging that many Programs are facing unprecedented challenges, including staff reductions, Special Olympics encourages all Programs to respond to the pandemic in the best way they can under the current circumstances. In this toolkit, we will outline two advocacy strategies around health equity your Program may want to use to engage stakeholders and the community around this issue. These strategies are:

1. Send a letter to your elected official(s)
2. Use communications to educate and move people to action

## What goals do we aim to achieve with these strategies?

During this challenging time, Special Olympics wants to:

* Ensure people with ID are treated with dignity during COVID-19 and do not face healthcare discrimination and medical resource discrimination/rationing by asking policy makers to
  + Require immediate, wide-scale health care provider and direct support staff training on working with people with ID during the pandemic
  + Ensure that detailed data about the experiences of people with ID around COVID-19, the quality of care they are receiving, and the allocation of limited medical resources are gathered and made publicly available
* Ensure that people with ID have equal access to COVID-19 testing, support needed to receive quality care, and plain language educational documents and tools on preventing virus spread by asking policymakers to
  + Designate people with ID as a priority population for COVID-19 testing and PPE in order to facilitate access
  + Guarantee that people with ID be allowed to have the support person of their choice available to them during COVID-19 care, testing, and treatment
* Provide/promote professional education to health care providers, direct service providers, and caregivers on best practices to protect people with ID and on the unique needs and barriers faced by people with ID in order to improve access to care (including primary care) during the pandemic and beyond.

## Who is the intended audience of this toolkit?

The Program staff best situated to move this work forward are:

* the person(s) in the Program who leads on advocacy matters (e.g., lobbyist).
* the person(s) handling Communications.

## How can you use this toolkit?

This toolkit contains a mix of guidance and turn-key contents to help implement the suggested strategies and move towards health equity for people with ID in the COVID-19 era.

Strategy #1 – Send a Letter to your Elected Official(s)

* This document provides instructions and sample copy for setting up a custom grassroots VoterVoice campaign. This campaign can help you engage your community in demanding that elected officials (e.g., governor, state legislators, federal Congressional representatives) take actions to ensure health equity for people with ID during the COVID-19 pandemic.
* Please note that the provided guidance and copy do not mention specific federal or state legislation. If your Program would like to modify the sample copy to mention specific legislation, remember that each Special Olympics Program is responsible for ascertaining their own obligations under state law and must follow state lobbying laws when advocating.Please do not make any federal legislative asks before consulting with the SOI Government Relations team (Meredith Pierce, [mpierce@specialolympics.org](mailto:mpierce@specialolympics.org) and Shawn Ferguson, [sferguson@specialolympics.org](mailto:sferguson@specialolympics.org)). Note that SOI’s Government Relations team may be able to provide assistance with state-level asks and is in the process of developing a tool that can help with flagging and monitoring relevant state bills.

Strategy #2 – Use Communications to Educate and Move People to Action

* This document provides plug-and-play messages for your Program’s social media channels. The messages highlight some of the crucial issues that people with ID have faced and continue to face during this COVID-19 outbreak.

Resources for Developing a Statement

* This document contains key messages to incorporate in any statement, as well as sample statements that SOI has issued on the topic of ID and COVID-19.

Appendix #1 – Additional Advocacy Opportunities and Strategies

* This document provides an overview of further issues of advocacy that your Program may wish to engage with stakeholders about. Even for those who do not intend to pursue these opportunities and strategies, this document provides valuable information about possible related issues and approaches, which may present opportunities for building new or solidifying existing partnerships.

### Appendix #2 – The Issue: Health Inequity for People with Intellectual Disabilities in the COVID-19 Era

* We include two versions of this advocacy two-pager focused on
* policymakers. One is a turnkey infographic-driven leave-behind,
* while the other goes in greater depth on the issues but is visually
* less friendly. Both include key information that highlights the particular  
  vulnerability of people with ID in the pandemic, as well as proposed
* action steps. Find the sources for information in both versions
* of the two-pager in the non-infographic version.

### Appendix #3 – Story Bank Information

* This document serves as a reminder about how storytelling strengthens advocacy initiatives. If you use this document or other instruments for storybanking, make sure you comply with applicable laws related to preserving anonymity, eliminating or protecting identifying information, and/or obtaining consent to share individual stories.

### Appendix #4 – What should an athlete do if s/he feels his/her rights have been violated

* This document is intended as a guide to the Program, to share with their Special Olympics community as they see fit and/or to share directly with an athlete and their support network, as applicable, if a potential rights violation of a Special Olympics athlete comes to the attention of Program staff.

### Appendix #5 – Know Your Health Rights

* This document is aimed at athletes, so that they can reflect on and evaluate any encounters they have had during COVID-19 in the health system. The intention is to help athletes enforce their rights, as well as report any possible violations to their rights.

## Practical Guidance for Using this Toolkit

* Advocacy is always more effective when it is not done in isolation. Identify other organizations and coordinate with partners in your advocacy approach to amplify the voice and need of people with ID.
* As always, Special Olympics athletes are the movement’s most important voices and most compelling storytellers and advocates. Please make sure any advocacy you may do is in close consultation with, and ideally led by, athletes.

# Strategy #1 – Send a Letter to your Elected Official(s): VoterVoice Instructions and Sample Copy

## What is VoterVoice?

VoterVoice is a digital grassroots advocacy tool that allows Special Olympics supporters to advocate on behalf of our movement. Through VoterVoice, Special Olympics Programs can ask their grassroots supporters to take action on various issues of importance. The process is simple for both Programs and for supporters: through the SOI HQ Government Relations team, Programs set up a campaign by identifying target government officials, writing a description of the issue, developing scripts for e-mail, Twitter and/or phone, and then   
sharing the campaign link through social media and newsletters to drive individuals to  
the campaign page.

Once on the campaign page, VoterVoice will guide supporters through the advocacy process based on parameters that Programs set. Supporters simply put in their name, address, e-mail address, and phone number to get started; the system automatically looks up to whom their outreach should be directed, based on their ZIP code and based on what government officials Programs have identified as the targets while setting up the campaign. VoterVoice will pre-load e-mail messages, tweets, and phone scripts (set by the Program) for each supporter—all they have to do is hit “send,” “tweet,” or “call.” Plus: for the e-mail and Twitter scripts, VoterVoice allows for the Program to set varying degrees of customization/editing on the supporter side. VoterVoice is a low-effort, high-impact way for Programs to engage supporters around issues the Program has identified, including those related to COVID-19.

## VoterVoice instructions

In order to set up a campaign in Voter Voice to activate your grassroots network, you will need to take several steps:

1. Consider the template message on the next page; identify the option highlighted in red text that is most relevant to what is going on in your state, incorporating input from athletes about their priorities; and craft additional asks tailored to your  
   state’s situation.
2. Do background reading and research, as needed, to help inform your strategy. Several elements you should think about are:

* Will you want to target the executive (e.g., governor) or legislative branch, or both?
  + If both, should the messages be identical, or how should they differ?
* Are there specific committees in the legislature you want to target?
* Should you target members of one or both chambers (if applicable)?
* Do you want members of your grassroots network to be able to modify the template message?
  + If so, do you want to retain approval authority before they can send it?
  + Tip: encourage athletes to create more personalized messages that they can include in the VoterVoice campaign and offer them support as needed (SOI HQ’s Government Relations team can back-stop here).

1. Contact Meredith Pierce at [mpierce@specialolympics.org](mailto:mpierce@specialolympics.org) for help setting up the VoterVoice grassroots call to action. She will tell you the information you will need to populate in the system and invite you to schedule a call to work through it together.

## VoterVoice campaign example and sample text



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### Background

People with intellectual disabilities (ID) tend to be less healthy than their peers in the general population: they have a high occurrence of health risk factors like obesity and diabetes and are at higher risk of respiratory disease, of influenza, of pneumonia, and of death from these causes. They may also be more vulnerable to COVID-19, particularly as many adults with ID live in group settings, where we have all seen how quickly COVID-19 moves through the population with often devastating effects.

Nevertheless, the most important risk for people with ID is not the underlying condition, but the lack of access to quality and affordable health care. Over 80% of health care professionals have not received training on how to treat people with ID and do not necessarily know how to communicate with people with ID or feel comfortable treating them.

6

The barriers people with ID face in the health system matter now more than ever with COVID-19. They can mean the difference between life and death. Health care professionals may not know how to communicate with people with ID about COVID-19 prevention and symptoms in a way that they understand. Hospitals are not set up to address the communication and sensory needs of people with ID. Health care professionals may not feel comfortable or confident conducting nasal swabs or other procedures on people with ID who may have a harder time cooperating. They may not be able to convey testing results, explain treatments, and give instructions in a way that people with ID can follow, understand and comply.

America/STATE is having difficult conversations right now about how to use limited medical resources, including personal protective equipment (PPE), COVID-19 testing, and intensive care equipment like ventilators. Numerous policy options under consideration prioritize healthier people for life-saving measures without asking how the less healthy got that way in the first place.

Please send a message to your elected officials reminding them that people with ID should not be sidelined, especially when it comes to health care, simply because that is where they have always been.

Equality and diversity are foundational American values. Prioritizing people with ID during the COVID-19 pandemic is an opportunity to put these values into action.

### Message

People with intellectual disabilities (ID) are particularly in need of proactive measures and protection from discrimination during the COVID-19 pandemic.

COVID-19 could severely affect the population of people with ID. The National Council on Disability estimates that around one-third of adults with ID in the US live in group settings, and a recent New York study cited in the *New York Times* estimated that residents in these settings are around five times more likely than the general population to develop COVID-19 and if they do get it, they are five times more likely die from it.

Designating people with ID as a priority population in the COVID-19 response is necessary to protect this population. Please take action:

1. Designate people with ID as a priority population for COVID-19 testing and PPE in order to facilitate access

1. Require immediate, wide-scale health care provider and direct support staff training on working with people with ID during the pandemic

1. Ensure detailed data about the experiences of people with ID around COVID-19, the quality of care they are receiving, and the allocation of limited medical resources are gathered and made publicly available

1. Guarantee that people with ID be allowed to have the support person of their choice available to them during COVID-19 care, testing, and treatment

1. Support funding to improve the health of people with ID during the pandemic  
   and beyond

# Strategy #2 – Use Communications to Educate & Move People to Action

The below content has been selected to plug-and-play on social media with the following goals:

1. Ensure people with ID are treated with dignity during COVID-19 and do not face healthcare discrimination and medical resource discrimination/rationing.
2. Ensure that people with ID have equal access to COVID-19 testing, support needed to receive quality care, and plain language educational documents and tools on preventing virus spread.
3. Provide/promote professional education to healthcare providers, direct service providers, and caregivers on best practices to protect people with ID and on the unique needs and barriers faced by people with ID in order to improve access to care (including primary care) during the pandemic and beyond.

* The most important risk people with intellectual disabilities face in the COVID-19 era is the lack of access to healthcare. Special Olympics Chief Health Officer Dr. Alicia Bazzano shares practical pointers for how health professionals can reach this population: <https://www.youtube.com/watch?v=_x3dQNb7IMo>
* Coronavirus lockdowns touched something deep in the community of people with intellectual disabilities. As Loretta Claiborne, a Special Olympics pioneer and Chief Inspiration Officer, put it: “Isolation isn’t new to me. I’ve dealt with it my whole life.” <https://www.washingtonpost.com/opinions/2020/05/13/isolation-isnt-new-those-with-intellectual-disabilities-covid-19-still-poses-threat/>
* The loneliness we have all felt during the COVID pandemic and quarantine is the status quo for many people with ID. Even before the COVID pandemic, many people with ID reported feeling lonely at 4 times the rate of the general population. <https://www.weforum.org/agenda/2020/04/covid-19-isolation-disabilities>, <https://www.weforum.org/agenda/2020/04/covid19-coronavirus-intellectual-disabilities-loneliness/>
* “[A] study by a large consortium of private service providers found that residents of group homes and similar facilities in New York City and surrounding areas were 5.34 times more likely than the general population to develop Covid-19 and 4.86 times more likely to die from it. What’s more, nearly 10 percent of the homes’ residents were displaying Covid-like symptoms but had not yet been tested…” <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html?referringSource=articleShare>
* “A nation should be judged by the way it treats its citizens who are most in need -- every day, but especially at times like this when we all feel vulnerable. We must focus our creativity and compassion on the needs of all by specifically addressing those who will be hit hardest.” <https://www.cnn.com/2020/04/23/opinions/disabled-americans-need-help-covid-19-cokley-besser/index.html>
* Doctors on the front lines are tasked with saving as many lives as possible, but in doing so, they must also protect America’s social fabric. People with intellectual disabilities are part of that social fabric. <https://www.theatlantic.com/politics/archive/2020/04/people-disabilities-worry-they-wont-get-treatment/609355/>
* Special Olympics supports health care professionals with training to help change these biases and achieve health equity for people with intellectual disabilities—during the COVID-19 pandemic and beyond. <https://learn.specialolympics.org/>
* Adults with intellectual disabilities (ID) are more likely to develop pneumonia than adults without ID. Pneumonia is one of the severe complications of COVID-19. Ensuring that medical professionals know about this increased risk is key to people with ID getting the attention they need in the COVID-19 era. <https://lernercenter.syr.edu/2020/04/27/covid-19-and-pneumonia-increased-risk-for-individuals-with-intellectual-and-developmental-disabilities-during-the-pandemic/>
* Johanna Schoeneck is a Special Olympics athlete who also works at a group home for other people with intellectual and developmental disabilities. “Hers is an intimate work. Not 6-feet-apart work. Not socially distant work. That means that the scores of people who need to avoid social interaction the most are the same ones who can’t avoid social interaction – indeed, must have it, often to eat and bathe and take medication. To survive.” <https://www.espn.com/specialolympics/story/_/id/29329465/special-olympics-athlete-johanna-schoeneck-front-lines-coronavirus>





# Resources for Developing a Statement

## Key messages

* People with intellectual disabilities (ID) are at greater risk than the general  
  population of contracting COVID-19, suffering complications from it, and dying from it.
* Three main factors put people with ID at greater risk:
  + Some people with ID have inherently higher risks. For example, people with Down syndrome may have compromised immune systems, which lead to higher rates of respiratory illnesses. People with cerebral palsy often have associated scoliosis or spine curvature and low muscle tone that produce higher risk of pneumonia and difficulties with secretions.
  + Many people with ID have the kind of health conditions that seem to make COVID-19 more difficult to recover from, like diabetes and high blood pressure. This population’s poorer-than-average health is because they lack access to quality health care—over 80% of health care professionals are not trained on working with people with ID.
  + A large number of people with ID live in group settings like group homes, where social distancing is difficult and staff may not have the most up-to-date training.
* People with intellectual disabilities are at risk of being de-prioritized for or disqualified from COVID-19-related medical attention, including life-saving measures, because of their poorer-than average health. This punishes people for factors that were out of their control in the first place and has the possibility of changing the face of society for the worse.
* The health system, including health education, must recognize the value and respond to the needs of vulnerable populations, like people with ID. [In the words](https://www.youtube.com/watch?v=nc9aAY6-ujQ) of Special Olympics athlete Danielle Liebl: People with ID “are just like any other patient. They have health problems, discomfort problems…It just may take a little bit more time to listen to what they have to say.”

## Examples

* Statement by Special Olympics New York President, Stacey Hengsterman - <https://www.specialolympics-ny.org/news/statement-by-special-olympics-new-york-president-ceo-stacey-hengsterman-on-covid-19-outbreak-in-nyc-group-homes/>
* Statement by Special Olympics Inc., Chief Health Officer, Dr. Alicia Bazzano - <https://www.specialolympics.org/stories/news/special-olympics-chief-health-officer-responds-to-covid-19-outbreak>

# A screenshot of a cell phone Description automatically generatedInfographic - The Issue: Health Inequity for People with Intellectual Disabilities in the COVID-19 Era