The COVID-19 pandemic has resulted in an increase in need for health care resources – from personal protective equipment to hospital beds to intensive care treatment and ventilators. If health care is not available to provide treatment to everyone who needs it, it is possible that health care providers will need to decide who gets limited health care resources and who does not.

Disability Rights Pennsylvania (DRP) filed a discrimination complaint with the U.S. Department of Health & Human Services’ Office for Civil Rights (OCR) and advocated with the PA Department of Health (DOH) for changes to its draft policies to ensure that people with disabilities are not placed at the bottom of the list for access to health care because of their disabilities or assumptions about their disabilities. As a result, the Pennsylvania Department of Health (DOH) revised guidelines released on April 13, 2020 (Guidelines) that better protect people with disabilities from discrimination.

DRP still has concerns about the Guidelines and will continue to advocate for people with disabilities on this issue. This Fact Sheet will summarize key points from the Guidelines and provide tips for advocacy relating health care rationing and effective communication during the COVID-19 pandemic.
What protections are available for Pennsylvanians with disabilities under the Guidelines in the event of health care rationing?

- No categorical exclusions. No person will be disqualified from receiving critical care solely on the basis of their disability. Health care providers cannot use a list of disabilities to de-prioritize those patients for critical care if rationing is implemented. As the Guidelines explain, such exclusions “will make many feel like their lives are ‘not worth saving,’ leading to justified perceptions of discrimination.”
- A prohibition on the reallocation of personal ventilators that adults with disabilities ordinarily use and bring with them when they seek care.
- No reference to specific disabilities as a basis to reduce the likelihood that those individuals will receive critical care.
- No consideration of life expectancy in the longer term, such as 10-year or longer life expectancy after critical care treatment.
- No one can “be denied care based on stereotypes, assessments of quality of life or judgments about a person's ‘worth’ based on the presence or absence of disabilities or other factors.”
- All rationing decisions must be based on individualized patient assessments by clinicians using the best available objective medical evidence. This means that rationing decisions cannot be based on discriminatory assumptions about a person's disability or medical condition.
- “Crisis Triage Officers” – the health care professionals who will be responsible to make any rationing decisions – should receive training on implicit bias and cultural competency.
- Patients and their family members or caregivers who have concerns about rationing decisions should be notified of their right to express their concerns or file a complaint with the hospital. Unresolved or unsatisfactorily resolved complaints can be brought to the Pennsylvania Department of Health.
Under the Guidelines, how would medical providers decide who gets limited health care resources if rationing is determined to be necessary?

If more people need critical care (such as ICU beds or ventilators) than is available, the Guidelines would allow physicians designated as Crisis Triage Officers to make rationing decisions using a two-step scoring process for grouping patients into priority groups:

- **Step 1:** Patients are assessed under a medical evaluation tool used to determine the likelihood that the patient would survive treatment for COVID-19 or other acute illness requiring treatment with limited medical resources. The usual tool will be the Sequential Organ Failure Assessment (SOFA) for adults and the Pediatric Logistic Organ Disfunction-2 (PELOD-2) for children age 14 and younger. These tools evaluate organ function (through assessment of a person’s respiratory, cardiovascular, hepatic, coagulation, renal and neurological systems). In step 1, patients are assigned up to four points with a higher number of points being assigned for worsening organ dysfunction.

- **Step 2:** The second step assigns additional points to patients whose likelihood of continued survival is limited due to underlying conditions – two points for those who are likely to die within five years and four points for those likely to die within one year.

Patients are then assigned to a color-coded group based on the total number of points.

*Graph Description: A Level of Triage and Code Color is designated in correlation to an Evaluation score from the Multi-principle Scoring system:
Red is the highest priority with a Priority score of 1-3.
Orange is an intermediate priority with reassessments as needed and a priority score of 4-5.
Yellow is lowest priority with reassessments as needed and a priority score of 6-8.*
Patients who receive critical care generally will be allowed to continue to receive care for a trial period. Care may be withdrawn from a patient after the trial period if there are other patients waiting for services and the patient receiving care is deteriorating. Care may be withdrawn from a patient before the end of the trial period if they experience a significant decline or a medical event that makes survival highly unlikely.

**What concerns does DRP continue to have about Pennsylvania’s Guidelines?**

First, in rationing care, the Guidelines allow health care providers to consider predictions about how long a person will live in the short term, including up to five years after treatment, due to a disability or medical condition unrelated to COVID-19. This rule could unfairly limit access to health care resources for people with disabilities.

Second, the Guidelines do not explicitly instruct health care providers that they are required under the law to make reasonable modifications to accommodate people with disabilities, including by:

- Making modifications to the assessment tool used under the Guidelines, such as SOFA, if a person cannot be accurately and fairly assessed due to a disability.

- Making modifications for people whose disabilities might require a longer period of treatment – for example, on a ventilator – in order to ensure an equal opportunity to benefit from the treatment.

- Providing effective communication to people with sensory disabilities and making modifications to restrictive visitor policies to allow individuals with disabilities who need family members or staff to accompany them in the hospital to ensure that they are properly assessed and can participate in their treatment.
What should you do if you are hospitalized and rationing is being implemented?

It is important to make sure that health care providers conduct an individualized evaluation based on the best available objective medical evidence. You or someone acting for you should be prepared to make sure that the providers have all information about your health that they need to make an individualized decision.

It is important that you or someone acting for you ask for any reasonable modifications necessary:

- Ensure that health care providers are aware of disabilities that may make components of the priority assessment not accurate or not possible. Examples include sensory disabilities that prevent verbal response to questions and chronic respiratory illnesses that impact baseline functioning unrelated to COVID-19 or other acute illness. Ask that the Crisis Triage Officer not lower your priority group based on these disabilities.

- If you have an underlying condition that requires a longer trial period for treatment to be effective, you should ask for a longer trial period as a reasonable modification. For example, if you need more time on a ventilator than the standard trial period being assigned to patients due to an underlying disability, you should ask for it.

- You should ask for any auxiliary aids and devices or other reasonable modifications to assure effective communication with health care staff. This can include sign language interpreters, written materials in alternative formats, or the presence of a “communicator” – a person who can facilitate communication for a person with a sensory or cognitive disability. These individuals should receive personal protective equipment to prevent the spread of infection.

If you are denied care or care is subsequently withdrawn or a request for a reasonable modification is denied, you or someone acting for you should request documentation supporting the decision.
What should you do if you are believe you were denied health care, if health care is withdrawn, if you are denied a reasonable modification or effective communication?

If you are denied care, if care is withdrawn, if you are denied reasonable modifications or effective communication, or if you have any other concerns about health care rationing, you or someone you know should take the following steps:

- Contact the hospital’s patient rights or patient advocacy department
- Contact DRP’s Health Care Rationing Hotline at 800-692-7443 ext. 402.
- Contact the Pennsylvania Department of Health at 800-254-5164

Stay Connected

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). Our email address is: intake@disabilityrightspa.org. DRP’s live intake line is open Monday-Friday from 9:00 a.m. to 3:00 p.m.

The mission of Disability Rights Pennsylvania is to advance, protect, and advocate for the human, civil, and legal rights of Pennsylvanians with disabilities. Due to our limited resources, Disability Rights Pennsylvania cannot provide individual services to every person with advocacy and legal issues. Disability Rights Pennsylvania prioritizes cases that have the potential to result in widespread, systemic changes to benefit persons with disabilities. While we cannot provide assistance to everyone, we do seek to provide every individual with information and referral options.

IMPORTANT: This publication is for general informational purposes only. This publication is not intended, nor should be construed, to create an attorney-client relationship between Disability Rights Pennsylvania and any person. Nothing in this publication should be considered to be legal advice.

PLEASE NOTE: For information in alternative formats or a language other than English, contact Disability Rights Pennsylvania at 800-692-7443, Ext. 400, TDD: 877-375-7139 or intake@disabilityrightspa.org.

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