Addressing Concerns About Healthcare Rationing

In light of the coronavirus pandemic, a recent resurgence of COVID-19 cases across the US, and questions about hospital capacity, the Down syndrome community has expressed concerns about the healthcare rationing. DSACT board member Suzanne Shepherd, a former attorney with the Seton hospital system, has provided background and current law on healthcare treatment, below.

‘On March 28, the Office of Civil Rights within the US Department of Health and Human Services put out a bulletin specifically protecting the medical rights of people with disabilities with respect to emergency medical services. This will override any local or hospital policy. You just have to know about it: hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf

‘At the same time, people with Down syndrome or other disabilities are not entitled to any greater priority with respect to medical resources, IF we get into a rationing situation. They are supposed to be on an equal footing. Equal footing is generally considered to be - take the number of years of expected life into account (a 20-year-old has more than an 80-year-old). And take into account underlying medical conditions that could impact survival - with the coronavirus, that’s obesity, hypertension, diabetes, heart conditions. So it’s possible a person with Down syndrome could be denied an ICU bed or a ventilator NOT because of Down syndrome, but because he or she has a number of underlying medical conditions. Bottom line: it would be blatant discrimination to deny intensive services to a person just because he has Down syndrome, and it’s illegal, but you have to discern why any denial of service is occurring, if it does occur.

‘If you think that's happening to your loved one, demand a meeting with the hospital ethics committee. Call the Office for Civil Rights within US Health and Human Services, contact
the Joint Commission (accrediting entity for hospitals), and the Texas Department of State Health Services (licensing entity for Texas hospitals).

DSACT recommends that families take steps now to optimize the health of their loved one with Down syndrome. Stay home, social distance if you go out, use a face mask, and focus on a strong immune system with exercise, eating well, sleeping well, and maintaining a healthy weight.”