Insufficient supply prevents many Americans from receiving health care services they might benefit from. Sometimes, as in the case of transplantable organs, both the processes and outcomes of allocating limited resources are highly visible. In other contexts, allocation proceeds more opaquely, as when physicians discharge patients from intensive care units to open beds for other patients. The ethics of both rule-based and “bedside” rationing hinge on how well each process promotes fairness, maximizes benefit, and gives priority to patients who are the worst off. Unfortunately, inevitable tensions arise when trying to balance equity, efficiency, and priority. Consequently, some people will feel mistreated.

Such perceived mistreatment fueled recent controversy surrounding Sarah Murnaghan, a 10-year-old girl dying of cystic fibrosis at the Children’s Hospital of Philadelphia. As her condition deteriorated, Murnaghan’s family and friends organized an impressive media campaign claiming that a policy preventing Murnaghan from receiving priority for lungs from adult donors discriminated against children.

This policy, enacted in 2010 by the Department of Health and Human Services (DHHS) Organ Procurement and Transplantation Network (OPTN), states that children younger than 12 years receive highest priority for lungs from donors younger than 12, secondary priority (behind adolescents aged 12 to 17 years) for donors aged 12 to 17, and lowest priority for donors 18 years or older.

Spurred by the Murnaghans’ public relations blitz, U.S. Senator Patrick Toomey (R-Pa) (2) and media outlets echoed the claim that this policy discriminated against children, and District Court Judge Michael Baylson imposed a 10-day restraining order against the DHHS. With Murnaghan (and ultimately, another child at the same hospital) thus given equal priority as adults for receiving lungs from adult donors, Murnaghan received a double-lung transplant from an adult donor before a full hearing could ensue.

This intervention sets a troubling precedent. The court did not seek evidence to assess the merit of the age-discrimination claim. Measuring this policy’s impact on different age groups requires careful consideration of the numbers of adults, adolescents, and children awaiting transplantation; the availability of donors in each group; and the expected benefit when patients receive donor lungs outside of their age range. Preliminary analyses presented by the United Network for Organ Sharing 5 days after the court decision showed no evidence that existing policy reduced lung access for children. Had expert testimony been allowed, it may have also become clear that absent the policy, far more adults would become recipients of children’s lungs than vice versa.

The rule undoubtedly disadvantaged Murnaghan, but the court’s response exalted her and another child above a national policy, suggesting either failure to recognize that preferential treatment for some recipients will adversely affect others (who may not be much older than 12) or that the court considered these 2 children’s lives more valuable than others. Neither of these explanations is satisfying. Further, by showing willingness to put national policies on hold to benefit individuals, the court established a broad tolerance for intervention. It might seem comparatively easy to issue restraining orders against individual physicians who must routinely deny chemotherapy due to drug shortages or establish queues in emergency rooms.

Sarah Murnaghan’s parents, who were fulfilling their duties to their own child, cannot be blamed for this circumvention of due process. Blame falls on the legal and political leaders who neglected their responsibility to protect the interests of all potential patients. These leaders bent the rules in favor of a well-resourced family that generated enormous media attention. The transplant community would be wise to heed this case as a clarion call for improving the supply and allocation of transplantable organs.

First, existing OPTN review committees should use more sophisticated modeling tools, such as the Scientific Registry for Transplant Recipients’ simulated allocation models, to compare access to lungs and outcomes after transplantation under the present and alternative age-stratification policies. If such models suggest that the population of patients awaiting lung transplantation would fare better by altering age-based prioritizations, then the policy should change accordingly.

Second, this case should motivate transplant physicians to more earnestly adhere not only to their duties to their own patients, but to their equally compelling duties to just distribution of resources. Current imbalance in these duties is evidenced by the practice of listing most patients with idiopathic pulmonary fibrosis and chronic obstructive pulmonary disease for double-lung transplantation, despite the absence of benefit relative to single-lung transplantation for most patients with idiopathic pulmonary fibrosis and evidence showing that double-lung transplantation for chronic obstructive pulmonary disease yields more deaths on the waiting list without increasing life-years gained overall. New policies that set explicit, evidence-based criteria for listing patients for double-lung transplantation would enable more patients to receive a transplant with the same supply of lungs.
Third, the transplant community should work to expand the lung supply by making better use of donors after circulatory determination of death. A population-based cohort study in the same region in which Murnaghan resides showed that the lung supply could be increased by as much as 50% (9) if more transplant centers used these organs.

Finally, this case should spur transplant centers to reconsider how they choose to accept donor lungs with blemishes, such as those from moderate smokers. Although such lungs may produce shorter survival than pristine organs, some patients may prefer to receive an imperfect organ sooner rather than waiting for a better one (10). Indeed, had Judge Baylson acted more assiduously, he might have heard evidence that many children listed for lung transplantation have multiple organs offered to them (3). If so, changing the allocation system may be a less effective solution than changing practices that influence transplant centers’ acceptance of available organs. To this end, public reporting of transplant center outcomes should be modified to reward, rather than to penalize, centers for taking risks on behalf of well-informed patients.

By embracing such changes, the transplant community can turn the political and legal wrongs of the Sarah Murnaghan case into a strong dose of right. Not only would these steps provide more patients with access to life-extending interventions, but by being more proactive the transplant community can protect the system it has worked so hard to build from future judicial intervention.

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Disclaimer: The author is a member of the Scientific Registry of Transplant Recipients Technical Advisory Committee and the Department of Health and Human Services Advisory Committee on Blood and Tissue Safety and Availability. The views expressed in this article are his own and do not necessarily reflect the views of these committees or the United States government.

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