care based on ability to pay. At the same time, pandemics such as the H5N1 "avian flu" still prompt public health officials to develop triage plans for how to ration scarce medical resources such as ventilators in the event of a major outbreak (see this chapter's Decision Scenario 8 for more details).

As for the ESRD program, it was modified by Congress in 2008 to "bundle" payments for dialysis, drugs, and other treatments, and to try to achieve better outcomes by instituting "pay-for-performance" incentives. (These changes anticipated many of the ACA's Medicare pilot programs, which aim to provide more efficient and coordinated care by bundling payments to a group of providers rather than reimbursing for individual procedures.) It remains to be seen how these changes will impact the ESRD program and what place they will occupy in the long and contentious history of allocating life-saving dialysis treatment.

CASE PRESENTATION

Transplants and Disability

Sandra Jensen was born with a defective heart, but it wasn't until she was thirty-five that it began to make her so sick that she needed a heart–lung transplant to save her life. She was young and otherwise healthy, but transplant centers at both Stanford University and the University of California, San Diego, rejected her as a candidate.

The reason the centers cited was that Sandra Jensen also had Down syndrome, and some of the transplant doctors doubted that she had sufficient intelligence to care for herself after the surgery. Like other all transplant recipients, she would have to follow a complicated daily medical regimen involving dozens of medications. If she failed to adhere to the postoperative requirements, she might die, and the organs that might have saved the life of one or two other people would be wasted.

William Bronston, a state rehabilitation administrator and friend of Jensen, became her advocate. He pointed out that she had demonstrated a high level of intellectual functioning. She was a high school graduate who worked with others with Down syndrome, and she had lived on her own for several years. She was an advocate for the disabled in California and attended the signing by President Bush of the Americans with Disabilities Act in 1990.

Thanks to a strong lobbying effort by Bronston and the threat of adverse publicity, Stanford reversed its decision. On January 23, 1996, in a five-hour operation, Jensen became the first intellectually disabled person in the United States to receive a major organ transplant.

Compliance and Discrimination

Since Jensen's transplant, patients with intellectual disabilities have made some progress in getting access to organ transplants, but data suggests that such impairments are still a major obstacle, especially in heart transplants. A 2008 survey of eighty-eight transplant centers reported that 46 percent of heart programs indicated that even mild or moderate cognitive impairment would be a contraindication to transplant eligibility. In addition, the International Society for Heart and Lung Transplantation's criteria for heart transplants states that "Mental retardation or dementia may be regarded as a relative contraindication to transplantation." Since roughly 50 percent of the 250,000 people in the United States with Down syndrome suffer from heart defects, such stances can have serious and fatal consequences for these patients.

What accounts for these policies? The most commonly cited reason is the one used by the transplant centers that initially rejected Jensen's candidacy: that intellectual impairment would undermine her compliance with medical directives and cause her transplant to fail. This stance is worthy of consideration, since noncompliance with post-transplant care is one of the leading causes of transplant failure.

But subsequent studies have found no indication of difference in medical compliance or post-transplant mortality between intellectually disabled and nondisabled transplant recipients. A 2006 literature review published in the journal *Pediatric Transplantation* found high levels of postsurgical care compliance among intellectually disabled patients, in part due to the consistent support networks on which they rely. In addition, the survival rates for these patients was comparable to those of nondisabled patients. A 2010 study published in the *American Journal of Transplantation* concluded, "Currently, there is no scientific evidence or compelling data suggesting that patients with MR [mental retardation] should not have access to organ transplantation."

Critics of continued consideration of cognitive impairment in organ transplantation point out that nondisabled children and infants are routinely approved for transplants when it cannot be assumed that they will comply with medical directions without extensive assistance. They argue that compliance is serving as a cover for judgments about the social worth of the mentally disabled, with institutions making subjective assessments of patients' quality of life rather than objectively assessing the quality of their health.

"Once you get into measuring quality of life, you are one step away from deciding between a doctor's and a janitor's lifestyle, or between a famous athlete and an obscure mother of two children," argues Len Leshin, a pediatrician specializing in Down syndrome.

Some ethicists, such as NYU's Arthur Caplan, have offered a qualified defense of discriminating against the intellectually disabled in transplant decisions, arguing in the context of age requirements that "If the potential recipient is severely intellectually impaired, or is basically almost in a coma, I do not think it makes sense to consider that child for a transplant either." Critics of this argument point out that this slippery slope runs in both directions, and that most people would be uncomfortable with restricting heart transplants to those with unusually high IQs.

Envoi

More than a year after Sandra Jensen's transplant, she was admitted to Sutter General Hospital in San Francisco. Her problem was not compliance with her immunosuppressive drug regimen, but a severe reaction to the drugs themselves—a common problem that had caused her to be admitted to the hospital several times before. She died of complications from the drug reaction on May 25, 1997.

"Every day was always precious and lived well by her," her friend William Bronston said of Jensen, after her death.

Jensen's struggle to be accepted for a transplant continues to inspire action and calls for reform. Prompted, in part, by Jensen's story, the California Assembly passed a bill in 1996 to prohibit transplant centers from discriminating against the physically or intellectually disabled unless such disabilities are "medically significant" to the transplant. But the situation is different in many other states. In January of 2012, Children's Hospital of Philadelphia denied a kidney transplant to a three-year-old child on the grounds that she had intellectual disabilities, until the ensuing national controversy forced the hospital to reverse its decision. This and similar cases make it clear that policies on transplants for the intellectually disabled remain inconsistent and unresolved across the United States.

BRIEFING SESSION

Few of us have as much as we desire of the world's goods. Usually, this is because we don't have enough money to pay for everything we want. We have to make choices. If we wish to take a vacation in Florida, we can't afford to buy a new phone. Sometimes, even when we have the money, we can't buy some item because the supply is inadequate or nonexistent. A manufacturer, for example, might not be turning out a new phone fast enough to meet the demand for it. Or, to take a different sort of case, we can't buy fresh figs in Minnesota in January, because they simply aren't available.

In some circumstances, we can't acquire an item because its supply is limited and our society has decided that it falls into a category of goods that require more than money to acquire. The item may then be formally rationed on the basis of social priorities.