

There Are All Kinds of Rights

BY PAUL S. APPELBAUM

Some years ago I received a phone call telling me that my mother, then in her eighties, had been found wandering the street outside her home. It was the first indication my wife and I had of Alzheimer's disease. We arrived to discover that my mother was incoherent, with the house in disorder, bills unpaid, and perishable food in the night table rather than the refrigerator. We took her to a hospital, where she was admitted without her consent. Subsequently, we began proceedings to have me, her only child, appointed as guardian, with the authority to pay her bills, find a safe place for her to live, and make medical treatment decisions.

Although my mother's condition followed the expected downhill course, her last years were comfortable and happy, in excellent facilities near her family. In her final days, we were all at her bedside. However, had we been unable to protect her when she was incapable of protecting herself, the story would have been very different—for me, unimaginably so. Having spent much of my career trying to improve the assessment of decisional capacity, in part to avoid unnecessary deprivation of decision-making rights, I did not take lightly the step to have my mother declared incompetent. But it was necessary.

This episode has been on my mind since I returned recently from a conference in Paris devoted to the United Nations Convention on the Rights of Persons with Disabilities. The Convention, much of which is exemplary, is premised on the inherent dignity of disabled persons and their rights to be free from discrimination. Article 12—the particular focus of the meeting—deals with “equal recognition before the law,” a principle that in the abstract is difficult to contest. But embedded in Article 12 is a provision that promises to cause untold harm to people with disabilities in the 160 countries (not including the United States) that have ratified the Convention.

Article 12(2) reads, “Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” Casual readers will probably find that unexceptionable, but it actually represents a radical assault on traditional approaches to protecting incapable

people. That becomes clear when one turns to the General Comment on Article 12, issued by the Committee on the Rights of Persons with Disabilities, established by the United Nations to oversee the Convention's implementation.

The Committee interprets Article 12 as indicating that “legal capacity is a universal attribute inherent in all persons by virtue of their humanity” and that “the existence of an impairment . . . must never be grounds for denying legal capacity.” As the General Comment makes clear, the formulation in Article 12 implies that decision-making power can never be taken from a person who desires to exercise it. No guardianships for incapable persons, no matter how impaired. No civil commitment of persons with severe mental

disorders who threaten themselves or others. No life-saving medical treatment over the objections of delirious patients.

I went to Paris hoping to understand how advocates for persons with disabilities could urge abandonment of those persons most in need of protection. I found what another skeptical participant called “a utopian vision,”

one disconnected from the everyday reality of people with severe impairments. Supporters of the Convention spoke of universal capacity as a “useful legal fiction” to promote disabled persons' rights, as though disabled people don't also have rights to protection. Nonetheless, officials in several countries appear to have accepted the Committee's interpretation and are urging their governments to adopt it.

Here in the United States, with our strain of American exceptionalism, it's often easy to ignore international declarations. But the Convention is worth attention from the bioethics community. We need to endorse the principles of nondiscrimination, equal access, and reasonable accommodations embodied in the document while affirming that people with severe disabilities also have rights to protection from the consequences of their conditions. Approaches such as supported decision-making that minimize use of surrogates, along with rigorous procedural protections, would be a more certain guarantee of the rights of persons with disabilities than leaving many of them defenseless in the name of autonomy.

The complexities of disability