Dorothy Wertz and I began to work together in 1984. We surveyed medical geneticists in nations with at least 10 board-certified or recognized practitioners. At the time, there were only 18 such nations. Our collaboration led to many co-authored articles and our first book. We were also part of a growing international network of geneticists, counselors, and scholars from law, philosophy, theology, social science, and other disciplines. Network members have two special marks. First, most of them are “friends of Dorothy.” The second is a commitment to raise the level of debate about social, ethical, and legal issues in human genetics.

Debate about ethical problems that lacks good information, in this case about how givers and recipients of genetic services and the public think about the problems, is like genetic counseling with no family history. It happens but is bound to be inadequate.

Dorothy worked between ethics, social science, and public policy. Ethics is a self-correcting process of fallible people deliberating to resolve conflicting moral principles and maintaining integrity. Good information can correct but not overcome fallibility. Dorothy nourished ethical debate with data about how geneticists, counselors,
practicing physicians, parents, and the public probably think about ethical issues in genetic services. Ethnography and interviews reveal moral reasoning better than surveys but can only be local. Surveys have limits but are better than inference as to what people think or are likely to choose.

Few know her uphill struggle to be a social scientist. After a PhD in religion from Harvard in 1969, Dorothy taught at Bryn Mawr College. The barriers in a male-dominated field were too high, and she eventually returned to the social sciences begun at Radcliffe. Instead of more graduate school, she taught sociology courses in seven different small New England colleges. Her apprenticeship did not take the familiar route up the academic ladder with its infrastructure of mentors and sponsors. Dorothy never had a salaried, tenured position. Support had to come from funded research. She won respect and funding because of her excellent work and good judgment.

With James Sorenson (1981) and others, Dorothy worked on the first major evaluation of genetic counseling. Critics of genetic services at the time argued that the practices encouraged abortion and a return to eugenics. Sorenson and his colleagues found that counseling often reassured parents with family history of genetic problems, and they had more children. More wanted children are born because of the education and support of counseling, because at an earlier time many parents at higher risk stopped having children. Dorothy was an expert on the reasons why counseling succeeds or fails. She wrote the classic paper on how counselees and counselors often pass like ships in the night (1988).

Cross-cultural research is hard to do and hard to get funded. Dorothy was the force behind a second survey in 37 nations, supported by the NIH. The questionnaire
was translated into thirteen languages. Kluwer will soon publish a book from this project, on which Dorothy worked so hard. She encouraged debate and education in each nation. Using cases in the questionnaire, some national genetics societies openly debated ethical issues for the first time.

Dorothy traveled to genetic centers all over the world. A familiar figure to geneticists and counselors in Germany and Canada, she was famous in China and other developing nations where women aspire to overcome traditional discrimination. With Dorothy’s help, some women who are geneticists in these nations found their moral voices. Their eloquent and brave writings will be in our book. Dorothy’s was a voice for justice in health care, education, and women’s rights all over the world.

At a life’s end, we should view a person by what happens to those around her, and not only by what she accomplishes. Some succeed only at others’ great expense. By this test, Dorothy’s life was so very positive. Her colleagues learned and grew personally and professionally. She was a giver and not a taker. Dorothy cultivated the arts of friendship and scholarship like no one else I have known.

As Dorothy aged, she made a first impression of eccentricity. When she entered a room or rose to speak, it was hard not to focus on her colorful garb, hats, or remarkable jewelry from all corners of the earth. That is, until she began to speak; then Dorothy had our full attention. Her voice lives on in our memories and in the work we share.
References


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