

## WHAT WE HAVE LEARNED FROM THE PROJECT ON DEATH IN AMERICA

GARA LAMARCHE

*Vice President and Director of U.S. Programs,  
Open Society Institute*



**B**EFORE GEORGE SOROS was inspired in 1996 to apply his foundation's resources to a broad range of open society challenges in the United States, he started with two: to spark a debate about harsh drug laws, and to change the culture of dying. No small tasks.

Yet less than ten years later, few would deny that huge progress has been made toward those goals. Not only has a debate about drug policy taken place, but state after state has considered or adopted reforms, from easing restrictions on medicinal use of marijuana to mandating drug treatment rather than prison for first-time offenders.

With respect to the care that people receive at the end of life, a once-taboo topic is now much more widely discussed in the media and in the academy and, much more importantly, in doctors' offices and hospital corridors and in family kitchens and living rooms. The simple but profound and universal goal that George Soros had in launching the Project on Death in America barely a decade ago—to improve the way that people die—is being reached for more and more people each day.

As we end the Project on Death in America, OSI can reflect on what we have learned from PDIA's leadership, which has had an enormous impact on all our foundation programs:

**That the personal is political.** Death is universal. Everyone must deal with it throughout life, first for loved ones, eventually for oneself. Every person has a stake in the discussion, some claim to expertise. And this insight has been important for OSI's work on drug policy, where virtually everyone has an experience with some kind of drugs, and the consequences for a friend or family member or community; or our work on criminal justice, where hardly any American, particularly urban dwellers, has been untouched by crime.

**How much leadership matters.** PDIA's flagship strategy has been to create and nurture a cadre of leaders in a new field: care at the end of life. By now touching virtually every healthcare institution, many special populations, and several professional disciplines, including social work and nursing as well as medicine, these individuals have transformed the way we think about and deal with dying. Taking a page from PDIA's strategy, other U.S. Programs have created fellowship programs to foster leadership in progressive criminal justice reform, community development, and reproductive rights. Drawing on what we learned through PDIA about the enormous influence and authority that physicians have, OSI also launched a special fellowship program to pair doctors with public

interest organizations working on a range of issues from human rights to the environment.

**How a small investment can be leveraged.**

OSI spent \$5 million a year on the Project on Death in America, but the needs of the field far exceeded that amount. From the beginning, PDIA worked closely with other funders in healthcare, aging, the arts, and other areas, and before long our investment was—happily—overshadowed by that of other donors, and served as a stimulus to the allocation of staff and budget resources by governments and healthcare institutions.

**How transformative a small amount of money can be.** Many PDIA grants, as you will read in this report, were not large. But sometimes a small amount of money can spark change, especially by the recognition it provides, the legitimacy it grants, the boost it provides. We've seen this lesson over and over again in OSI's grants over the years.

**Why systemic change is important.** At the same time, dealing with a vast, complex, and contested area of the economy like healthcare, PDIA realized over time that more needed to be done than change institutions one patient, doctor, or social worker at a time. If palliative care was to be more firmly established, for example, Medicare reimbursement policies needed to be changed. And that kind of policy work takes advocacy—the mobilization of people and organizations to educate and influence decisionmakers. This path from the funding of direct services to the call

for more systemic, enduring change has been followed by many other OSI initiatives in areas from immigrant rights and indigent defense to afterschool and drug treatment programs.

**Why reflectiveness and adjustment matters.**

Finally, a foundation or any institution seeking to make change must step back from time to time, look at what it is doing, and make any adjustments that are necessary in light of experience. This requires an honest assessment of what is working and what is not. Some of PDIA's early requests-for-proposals resulted in seeding important initiatives, others resulted in efforts that seemed too scattershot or lacked the rigor to be evaluated or replicated. Changes were made, some programs abandoned. As a broader institution, OSI has done the same, and tried to share its lessons with others in philanthropy and in the particular fields we support, as in the independent report we commissioned on the work of the Emma Lazarus Fund or our work on gun violence. If we are unwilling to look at our mistakes at the same time as we trumpet our successes, we are missing an important part of the picture.

Few foundation initiatives anywhere, on any subject, have acted with the discipline, honesty, openness, and impact that the Project on Death in America has maintained from the beginning. This will continue to be reflected for many years to come not only in a transformed culture of dying in the United States, but in everything else the Open Society Institute does.