Governments play a major role in the development process, and constantly introduce reforms and policies to achieve developmental objectives. Many of these interventions have limited impact, however; schools get built but kids don’t learn, IT systems are introduced but not used, plans are written but not implemented. These achievement deficiencies reveal gaps in capabilities, and weaknesses in the process of building state capability. This book addresses these weaknesses and gaps. It starts by providing evidence of the capability shortfalls that currently exist in many countries, showing that many governments lack basic capacities even after decades of reforms and capacity-building efforts. The book then analyzes this evidence, identifying capability traps that hold many governments back—particularly related to isomorphic mimicry (where governments copy best practice solutions from other countries that make them look more capable even if they are not more capable) and premature load bearing (where governments adopt new mechanisms that they cannot actually make work, given weak extant capacities). The book then describes a process that governments can use to escape these capability traps. Called PDIA (problem-driven iterative adaptation), this process empowers people working in governments to find and fit solutions to the problems they face. The discussion about this process is structured in a practical manner so that readers can actually apply tools and ideas to the capability challenges they face in their own contexts. These applications will help readers devise policies and reforms that have more impact than those of the past.
Over a period of almost ten years, the work of the Project on Death in America (PDIA) played a formative role in the advancement of end-of-life care in the United States. The project concerned itself with adults and children, and with interests crossing boundaries between the clinical disciplines, the social sciences, arts, and humanities. PDIA engaged with the problems of resources in poor communities and marginalized groups and settings, and it attempted to foster collaboration across a range of sectors and organizations. This book examines the broad, ambitious conception of PDIA—which sought to “transform the culture of dying in America”—and assesses PDIA’s contribution to the development of the palliative care field and to wider debates about end-of-life care within American society. Chapters consider key issues and topics tackled by PDIA grantees which include: explorations of the meanings of death in contemporary American culture; the varying experiences of care at the end of life (in different settings, among different social and ethnic groups); the innovations in service development and clinical practice that have occurred in the US in response to a growing awareness of and debate about end of life issues; the emerging evidence base for palliative and end-of-life care in the US; the maturation of a field of academic and clinical specialization; the policy and legal issues that have shaped development, including the ethical debate about assisted suicide and the Oregon experience; the opportunities and barriers that have been encountered; and the prospects for future development. A final chapter captures developments and milestones in the field since PDIA closed in 2003, and some of the challenges going forward.

A Brief History of the Project on Death in America

David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

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This chapter presents a brief history of Project on Death in America (PDIA) from its pre-beginnings to its closure. It explains how the initiative came about, how it was resourced, structured, and governed—and the programs that it developed and supported. The PDIA was unveiled publically on November 30, 1994, when George Soros gave an Alexander Ming Fisher Lecture in the Columbia Presbyterian Medical Center in New York. He identified three major recommendations. First, improved training for professionals involved in the care of the dying. Second,
the adoption of a comprehensive Disease Related Group (DRG) for terminal care in hospitals. Third, the increased availability of hospice services for terminally ill patients, without restrictions on admission and reimbursement.

Exploring the Meanings of Death
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

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Item type: chapter

This chapter examines the PDIA-funded work that emerged from the arts and humanities program. It considers activities exploring the meaning of death that were supported from generic grants and through a number of other special initiatives. It presents examples of community engagement projects, artistic endeavors, and some research studies. These activities demonstrate how PDIA gave expression to a range of work that allowed for the elucidation of meanings relating to death, dying, and bereavement in modern America—and in turn how it provided a framework for thinking about the configuration of end-of-life care services.

Highlighting Experiences of Care
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

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This chapter explores the different aspects of PDIA grant making and shows how they set the scene for further work that brought about innovations in policy and practice. PDIA, for instance, supported some outstanding work on the elucidation of personal experience at the end of life, from the perspectives of patients, families, and caregivers. In addition to clinical and individual perspectives on the experience of care at the end of life, PDIA also promoted the exploration of issues at the community level, seeing here an opportunity to engage in situated
debates about care that reflected the concerns and views of people as citizens as well consumers of services.

Service Innovation and Practice Developments
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

This chapter explores PDIA-funded solutions to problems in the delivery of end-of-life care. It considers the various service innovations across inpatient and domiciliary settings, as well as new developments in clinical practice relating to people with advanced disease in the face of death. Undertaken by numerous PDIA grantees and scholars, these were the testing grounds for new ideas, some of which would prove worthy of wider dissemination and “roll out”—moving beyond the status of demonstration projects to have a wider influence on the entire American health-care system.

Opportunities, Barriers, and Underserved Communities
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

This chapter discusses the PDIA board's policy work and its growing commitment to the needs of disadvantaged and dispossessed individuals, groups, and communities. The PDIA board's early policy initiatives embraced the challenge of evaluating and advocating for change relating to dying and bereavement—at federal, state, and local levels. They also acknowledged the role of large health-care delivery systems, plus government reimbursement for services, as well as workforce development issues. PDIA work relating to underserved communities is best described as a patchy and rather idiosyncratic field of endeavor populated by activists high on commitment to service delivery, but with rather less inclination for research and publication.
Ethical, Legal, and Financial issues
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

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This chapter discusses the various issues encountered by the PDIA relating to the provision of end-of-life care. These include the question of assisted suicide; clinical and organizational issues such as advance directives, health-care proxies, and informed consent; and legal and financial matters in end-of-life care.

Developing the Field
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

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This chapter discusses how PDIA influenced the field of palliative and end-of-life care through the promotion of research, education, and training activities. An examination of PDIA involvement in each of these realms and the level of progress made then highlights some core aspects of how PDIA sought to make a long-term impact on the culture of dying in American society and the particular role of the caring professions within that.

Assessing the Impact of the Project on Death in America
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America

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This chapter assesses the work of the PDIA, focusing on three areas. First, it examines the way in which PDIA was structured and organized and offers some reflections on its administration and management. Second, it explores the special contribution made by the faculty scholars. Third, it considers the impact of the whole PDIA initiative and explores the extent to which the venture was successful in meeting its ambitious goal.

A Culture Transformed? Post-PDIA Progress in Palliative and End-of-Life Care
David Clark

in Transforming the Culture of Dying: The Work of the Project on Death in America
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Item type: chapter

This chapter sets out some of the developments in palliative and end-of-life care in the United States in the decade following the closure of the PDIA in 2003. It explores three areas. First, it assesses the continuing role of philanthropy in shaping the field that was defined by PDIA and other interventions. Second, it looks at key actions, studies, publications, and debates that infused the field in the post-PDIA decade—and finds many rich examples of activity, innovation, and growth. Third, it reviews the continuing challenges that face the field in the American context, and the various propositions about how they might be addressed.

Managing your authorizing environment
Matt Andrews, Lant Pritchett, and Michael Woolcock

in Building State Capability: Evidence, Analysis, Action
Published in print: 2017 Published Online: February 2017
Item type: chapter

This chapter addresses authority in the PDIA process, given that authority is needed to make change happen. This authority is often difficult to attain, however. It is seldom located in one office or person, and is often difficult to lock in with complex challenges. This is because such challenges involve significant risk and uncertainty and require engagement by many agents responding to different authorizers. Efforts to address such challenges should include an explicit strategy to
establish an appropriate authorizing environment. This chapter suggests ideas to adopt in a strategy, emphasizing different types of authority and authority failures one commonly sees in development. It includes practical exercises and examples to help readers apply such thinking in their own work. As with past chapters, we believe that the ideas and tools here will equip readers to identify and energize a new and effective approach to addressing complex challenges.

The big stuck in state capability
Matt Andrews, Lant Pritchett, and Michael Woolcock

in Building State Capability: Evidence, Analysis, Action

Many developing countries and organizations within them are mired in a “big stuck,” or what we will call a “capability trap”: they cannot perform the tasks asked of them, and doing the same thing day after day is not improving the situation; indeed, it is usually only making things worse. We offer examples of this in the current chapter and use empirics to show that most governments seem especially prone to continued failure, even after decades of efforts to build state capability. We argue that this (and other) evidence suggests the need for deep reflection on past efforts to build state capability, and perhaps even dramatic changes to the way this is done in the future. This discussion lays a foundation for the rest of the book, which offers a diagnosis of the causes of “capability traps” in development and a strategy to escape such traps, using problem-driven iterative adaptation (PDIA).

The Searchframe
Matt Andrews, Lant Pritchett, and Michael Woolcock

in Building State Capability: Evidence, Analysis, Action

This chapter focuses on taking action in PDIA, performing real-time experimental iterations aimed at achieving quick wins to facilitate learning about the context and the effectiveness of potential solutions to the focal problem. It begins with “crawling the design space,” where one recognizes that there are always multiple ideas from which to draw
solutions. These ideas facilitate experimentation, which occurs in rapid iterations where teams take action, reflect on experience, and then act again. Each iteration allows teams to learn by doing, and adapt their actions in response to the learnings. We offer various tools to use, including a Searchframe. This is an adaptation of the Logframe currently used in many development organizations. The Searchframe gives structure to the adaptive process, giving policymakers a tool to communicate end goals, learn, adapt, and progress. Readers can use such tools to structure their own iterative strategy to address stubborn challenges.