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Chapter 8

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A history of the project on death in America: programmes, outputs, impacts

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6 From 1994 to 2003 the Project on Death in America (PDIA) played a prominent part in
7 end-of-life care innovations in the USA. PDIA produced a wide range of innovative
8 activities that explored the meanings of death in American culture and highlighted
9 experiences of care at the end of life. It led to extensive service development and practice
10 innovation. It contributed to the evidence-base for palliative care and the emergence of a
11 new field of specialization. It addressed the needs of underserved communities at the
12 end of life and barriers to improved care, as well as legal and ethical challenges. PDIA
13 generated strategies for ‘transforming’ the culture of end-of-life care, by empowering
14 individuals and communities promoting organizational change; encouraging research
15 and educational activities; and supporting public debate together with the consideration
16 of ethical issues. The project occurred at a time of major philanthropic interest in end-
17 of-life issues, so its impact is difficult to disentangle from that of other funders and
18 initiatives. But undoubtedly it made a significant and enduring contribution to the
19 improvement of end-of-life care in the USA.

20 Its inspiration came from the personal experience of George Soros, billionaire financier
21 and energetic private philanthropist (Soros 1995; Soros 2002; Kaufman 2003). Born in
22 Budapest in 1930, Soros studied at the London School of Economics where he found
23 inspiration in the work of the philosopher Karl Popper and established a life-long
24 preoccupation with the value of pluralist, multicultural ‘open societies’ (Popper 1945).
25 After years of financial success on the international markets and on the basis of a huge
26 personal fortune, he founded the Open Society Institute (OSI) in the USA in 1993,
27 building on the work of a network of foundations active across more than 50 countries
28 and with a combined annual budget of some \$400 million.

29 Established in 1994, PDIA was Soros’ first USA-based philanthropic initiative. It sought
30 to promote a better understanding of the experiences of dying and bereavement and to
31 help transform the culture surrounding death. This chapter provides a brief account
32 of the PDIA from its pre-beginnings to its closure. It explains how the initiative came
33 about, how it was resourced, structured and governed – and the programmes that it
34 developed and supported, together with some assessment of their impact. A full account
35 of the history of PDIA will be published in 2010; this chapter draws on that work and the
36 author’s interviews with named individuals in the PDIA programme.



1 Why a project on death in America?

2 In 1992 New York social worker Patricia Prem, an old friend of George Soros, was tasked
3 by him to find out more about the provision of care for people at the end of life in the
4 USA. She contacted a group of experts from clinical and academic backgrounds, as well
5 as some policy oriented and community activists. By early 1994 a series of meetings was
6 in train that culminated in the creation of an expert board and an offer of funding support
7 from the OSI to take forward an initiative in the area of death, dying and bereavement.
8 Some \$15 million was to be set aside over 3 years with the goal of improving the experi-
9 ence of death and dying in the USA.

10 The board charged with delivering the programme was handed a job of major signifi-
11 cance both in terms of the level of resource and also the manner in which it would be
12 deployed. The sense of responsibility was palpable. It soon became clear, however, that
13 the board was an ‘extraordinary cast of people’,¹ which worked together in a manner
14 akin to evangelists dedicated to the promotion of a cause. The members were open to
15 the many proposals and suggestions that came to them, but also contributed a huge
16 amount of their individual concerns and interests. In the early days they spent time
17 together on retreats and shared personal experiences; for several of them the involve-
18 ment proved to be life changing. They had a great deal to draw on and encompassed
19 high-level achievers in academic, clinical medicine, and health-related research; they
20 included a distinguished historian and social critic, a social worker and social activist, a
21 geriatrician, and a lawyer. The talents of the board were indeed extensive and they
22 needed to be, for as one member put it, the brief they had been given by Soros ‘was
23 breath-takingly open-ended’.²

24 Just 10 individuals served on the board through the lifetime of PDIA – five of them for
25 the full duration. Throughout the period palliative care leader and distinguished neurolo-
26 gist and pain expert, Dr Kathleen Foley, held the unusual position of being a member of
27 the board and the Director of the project. The *modus operandi* of the board was ‘hands on’
28 and engaged in depth with applications for funding, with monitoring progress as well as
29 with strategy and longer term direction. Throughout the lifetime of the project the board
30 was the key driver, shaping programmes, seeking out new opportunities, setting policy,
31 and reviewing progress. It resulted in a rich, varied and extensive programme of initia-
32 tives over almost a decade.

33 Programmes and grants 1994–2003

34 PDIA was unveiled publically on 30 November 1994, when George Soros gave an
35 Alexander Ming Fisher Lecture in the Columbia Presbyterian Medical Center, in New
36 York. The lecture began with an account of the death of each of his parents – his father
37 in 1963 and his mother more recently. These more reflective elements led on to a hard-
38 hitting critique of the culture of dying in modern America:

39 We have created a medical culture so intent on curing disease and prolonging life that it fails to
40 provide support during one of life’s most emphatic phases – death. Advances in high technology



1 interventions have deluded doctors and patients alike into believing that the inevitable can be
2 delayed almost indefinitely.

3 (Soros 1998: 5)

4 The speech identified three major recommendations: improved training for profes-
5 sionals involved in the care of the dying; the adoption of a comprehensive Disease Related
6 Group (DRG) for the funding of terminal care in hospitals; and increased availability
7 of hospice services for terminally ill patients, without restrictions on admission and
8 reimbursement. With 2.2 million people dying in the USA every year, the task seemed
9 enormous and those taking forward the PDIA would, he remarked in passing, 'have their
10 work cut out for them' (Soros 1998: 6).

11 With such a challenging brief, the PDIA board sought from the outset to foster coop-
12 eration and collaboration among the various professionals with cognate interests already
13 working in nursing, medicine, social work, ethics, policy, financing, as well as philan-
14 thropy and the media. Encouraged by Kathleen Foley, the board developed a regular
15 practice of identifying experts from different disciplines, and convening meetings to map
16 the field and determine the most pressing needs. The board members approached these
17 meetings with a sense of deep conviction, but also one of working without a net – as naïve
18 neophytes in the world of major philanthropy (PDIA 2004: 9). The early discussions were
19 extensive and probing; the initial strategy was exploratory and tentative.

20 In 1995, PDIA announced a grants programme to address seven priority areas for
21 funding, hoping to cast a broad enough net to address the many significant areas of need.
22 It was in a context of 'complete freedom to formulate our own agenda for transforming
23 the culture of death and care of the dying' (PDIA 2004: 17) that the programme emerged
24 and in which two interlocking themes were dominant: the harms inflicted by the medical
25 system on dying people and the harms caused by public attitudes about death itself, the
26 so-called 'denial of death'. The seven areas to be covered ranged from epidemiology and
27 ethnography to the shaping of governmental and institutional policy. In both its size and
28 range the response to the Request for Applications (RFA) was overwhelming and it
29 became the perfect tool to assess the range of interest in death-related topics across
30 America. In practice, however, it also led to a very broad range of initial investments,
31 some of which bore fruit while others did not.

32 In its first 3 years, PDIA received more than 2000 grant requests over four grant calls and
33 it funded 122 projects in the seven priority areas. Grants ranged from \$5000 to \$400,000,
34 and represented many different approaches to the subject of dying – from the medical to
35 the philosophical to the political. The board chose to fund a broad range of initiatives to
36 reflect the complexity of the medical and societal challenge of providing appropriate, com-
37 passionate care to dying people and those close to them.³ Eventually, three grant cycles
38 unfolded as the PDIA was extended from 3 years to 6 years, and then to 9 years.

39 From an early stage the PDIA board began to forge the view that it was essential
40 to change the culture of medicine in hospitals and nursing homes, where 80% of
41 Americans die. The board envisioned a national network of role-model healthcare
42 professionals – nurses, physicians, and social workers – who would serve as champions of



1 palliative care in their institutions. More than half of PDIA's funds were eventually to be
2 used to support professional education initiatives.

3 Central to this was the PDIA Faculty Scholars Program. In total 87 individuals (52 men
4 and 35 women) in eight cohorts were supported by the programme.⁴ Medical profession-
5 als dominated the programme overwhelmingly. Medicine, oncology, geriatrics and
6 psychiatry were the prominent disciplinary backgrounds, with just 10 nurses and three
7 social scientists taking part. The Scholars represented a total of 59 medical schools, 10
8 nursing institutions and two universities. For the most part each Scholar was funded for
9 3 years. The Faculty Scholars Program became hugely influential. It was widely regarded
10 on the board as being the single most successful aspect of PDIA, and the 87 Faculty
11 became among the most prominent and active leaders of palliative care in the USA.

12 There were those in the board who considered that this model could be extended to
13 other professions and that indeed there was a need to address the heavy physician domi-
14 nance of the programme by promoting the work of other groups involved in end-of-life
15 care. Most obvious among these was the nursing profession. PDIA supported nurses
16 through a Nursing Leadership Institute in End-of-Life Care to advance the profession's
17 agenda to improve care at the end of life by increasing relevant leadership capacity of
18 nurses. Some board members also argued – in the face of resistance – for greater promi-
19 nence to be given to social work perspectives in end-of-life care. The result was the Social
20 Work Leadership Program, which began in 2000 and encouraged social work applicants
21 to submit proposals addressing a critical issue in the care of the dying. Especially sought
22 after were projects that addressed the design, implementation, and dissemination of
23 research on new social work service-delivery models for the dying and their network
24 of family and friends. The result was a late rally for social work within PDIA and a
25 programme involving 42 social workers – 50% academics with PhDs and 50% with
26 Masters qualifications and working in direct practice.

27 These major professional development programmes took a significant share of the
28 PDIA budget, but funds were also used in innovative ways to support a variety of other
29 activities, reflecting the board's inclusive approach to transforming the culture of dying
30 within American society. One approach was to make alliances with other foundations
31 and philanthropic groups to raise awareness about end-of-life issues and to promote
32 more interest in grant making for improved end-of-life care. In a climate of growing
33 interest among private foundations in the subject of end-of-life care, PDIA joined forces
34 in 1995 with the Robert Wood Johnson Foundation, the Nathan Cummings Foundation,
35 the Rockefeller Family Office, and the Commonwealth Fund to form *Grantmakers*
36 *Concerned with Care at the End of Life*. This coalition organized conferences and shared
37 information in order to inform funders about major social, economic, and medical issues
38 in end-of-life care, and to encourage them to address those issues in their grantmaking.
39 A similar initiative occurred in 2002, when PDIA and the Emily Davie and Joseph S.
40 Kornfeld Foundation formed the Funders' Consortium to Advance Palliative Medicine.
41 This alliance supported existing and new palliative care fellowship training programmes,
42 with the goal of helping to increase the numbers of physicians with advanced training in

1 palliative medicine, and thereby make a contribution to the wider goal of obtaining for-
2 mal recognition as a medical subspecialty with the Accreditation Council for Graduate
3 Medical Education and the American Board of Medical Specialties. In 2006, the Council
4 and the Board approved and recognized the new specialty in hospice and palliative medi-
5 cine, and formal certification of physicians and accreditation of training programmes
6 began in 2008.

7 PDIA launched an arts and humanities initiative in 1998. Grantees produced film,
8 photography, poetry, essays, dance, and artwork to express individual and community
9 experiences of illness, death, and grief, and encourage conversation and thoughtful
10 reflection. Again, there was not unanimity on the board about the success of this initiative.
11 Nevertheless, the arts and humanities programme funded an innovative range of projects –
12 capturing cultural expressions of death and dying in exhibitions, theatre, film and video
13 documentary, poetry, photographs and essays, performance work, and even the unusual
14 medium of fabric and thread work. It made 14 grants to 13 grantees and highlighted the
15 role of creative artists in giving form though language and image to experiences at the end
16 of life, to promoting expressions of illness, death and mourning, and thereby helping to
17 ‘identify leverage points for change within our society’ (PDIA 2001: 40).

18 In 1999, a community grief and bereavement initiative was launched. From interfaith,
19 community-based, and school-based programmes to programmes for special groups
20 such as incarcerated youth or union home healthcare workers, grantees created
21 programmes to support individual and community bereavement. PDIA also chose to
22 address challenging legal and economic barriers, and to improve access to care for par-
23 ticularly vulnerable populations, and those socially excluded and denied access by the
24 healthcare system. These underserved groups included children, elderly persons,
25 non-English speakers, those incarcerated, the homeless, ethnic and cultural minorities,
26 and people with physical or developmental disabilities. PDIA also launched an initiative
27 to improve palliative care in the African-American community, recognizing that mem-
28 bers of this section of the population use relatively few palliative and hospice services,
29 even when they have full access to them. Little data existed to explain this phenomenon,
30 although historical denial of access to healthcare and past abuses in medical research may
31 have contributed to a general mistrust of the healthcare system (Brunner 2009). This
32 initiative sought to define and promote a research, education, and policy agenda, and to
33 build coalitions among organizations and stakeholders working in the African-American
34 community to promote palliative care.

35 In 1998, when 1.83 million men and women were incarcerated in prisons and jails
36 across the USA, more than 2500 prisoners died of natural causes in state and federal cor-
37 rectional facilities. Longer sentences and fewer paroles, coupled with the increasing age of
38 prisoners, were also contributing to the increasing numbers of terminally ill inmates. In
39 response, PDIA and the Center on Crime, Communities, and Culture, another OSI
40 programme, co-sponsored the first-ever meeting devoted to the growing problem of
41 caring for the dying in prisons and jails in order to define the issues and explore possible
42 solutions. PDIA also supported the production of a compelling video documentary on





1 one of the nation's first prison hospice programmes at Angola Prison in Louisiana, involv-
2 ing inmate volunteers trained to care for other dying inmates. As a result of these efforts,
3 a series of ongoing initiatives was developed to advance the care of dying prisoners
4 through the creation of educational initiatives for prison healthcare professionals and
5 associated policy changes. In collaboration with the Robert Wood Johnson Foundation,
6 PDIA supported the development of national guidelines for palliative care in America's
7 prisons and jails.

8 The PDIA was funded over a series of 3-year budgetary cycles. Towards the end of year
9 two of the first cycle the PDIA board put forward a tapering budget totalling \$12 million,
10 which would lead to closure after two cycles and a total of 6 years. In fact PDIA in due
11 course entered a third funding cycle – again at \$15 million – making a total funding
12 period of 9 years in all, from 1994 to 2003.

13 **Exit strategy and wider implications**

14 During the final year of its operation, the staff and board of PDIA reviewed the original
15 funding strategies, goals, and individual initiatives in the light of an end to OSI funding.
16 The need for an exit strategy, albeit one that had been postponed, proved a painful
17 experience for those concerned, who found it hard to imagine the programme ending.
18 The exit strategy focused around support for a number of key organizations active across
19 the USA in the field of end-of-life care. One major beneficiary stood out, however, and
20 this was the American Academy of Hospice and Palliative Medicine – a physician-based
21 professional organization dedicated to advancing practice, research, and education in
22 palliative medicine. PDIA awarded a \$1.2 million grant to the Academy to support its
23 infrastructure and to strengthen its ability to serve the needs of palliative care profession-
24 als through the creation of an academic 'college' to house the legacy and leadership of the
25 PDIA Faculty Scholars as well as to strengthen the Academy's capacity to support and
26 nurture academic leaders in all fields and to expand its role in the promotion of interdis-
27 ciplinary professional education in palliative care.

28 In contrast other exit grants were relatively modest. Three groups each received a grant of
29 \$200,000: the Hospice and Palliative Nurses Association; the Social Work Summit on
30 Palliative and End of Life Care; and the National Hospice and Palliative Care Organization.
31 Two grants of \$100,000 dollars each were awarded to: the Harvard Medical School's
32 Program in Palliative Care Education and Practice, and to the American Board of Hospice
33 and Palliative Medicine to implement standards for fellowship training programmes in pal-
34 liative care and to begin the application process to make palliative medicine a subspecialty.

35 With this programme of exit funding, PDIA completed all grantmaking at the end of
36 2003. In October 2004 the project issued a special report, *Transforming the Culture of*
37 *Dying*, in which its activities over a 9-year period were reviewed (PDIA 2004). The PDIA
38 invested \$45 million in improving care available to patients and their families at all stages
39 of serious illness. The report highlighted examples of strategic grantmaking and included
40 specific funding recommendations focused on areas of special opportunity where
41 philanthropic investment might make a dramatic difference to the lives of dying people



1 and their families. The report emphasized the enormous impact of private philanthropy
2 on the development of palliative and end-of-life care services in the USA and highlighted
3 OSI's interest in sharing with the greater funding community those lessons learned over
4 the lifetime of the PDIA. It also asserted that all people with serious or advanced illness
5 should expect and receive reliable, skilled, and supportive palliative care in order to
6 relieve pain and other physical symptoms, and to promote the highest quality of life
7 possible at all stages of serious illness. It acknowledged that palliative care can be deliv-
8 ered alongside potentially curative treatments and is best delivered by an interdisciplinary
9 healthcare team that can address physical, psychological, and practical problems.

10 Over 2.5 million individuals die in the USA each year. Many more tens of millions
11 are affected as bereaved relatives, companions, friends and caregivers. PDIA drew
12 attention to this set of social circumstances and sought to explore the consequences and
13 implications – and most importantly what might be done about it. From its beginning,
14 PDIA focused on the vulnerable and voiceless individuals who had, in a sense, been
15 abandoned by the healthcare system. Their suffering suggested ways in which modern
16 high-technology medicine had lost its way. PDIA took the view that palliative care
17 and treatment enhance the field of medicine and demonstrate the importance of both
18 competence and compassion in modern healthcare practice.

19 The goal of PDIA was ambitious and at the same time unmeasurable: to transform the
20 culture of dying in the USA. This was a huge societal challenge to be taken on by a fixed-
21 term programme funded through private philanthropy. PDIA was a *necessary* but not
22 *sufficient* condition for such a transformation to take place.

23 It has been observed (Eikenberry & Nickel 2006) that around the world many political
24 systems show evidence of a shift from hierarchically organized and unitary systems of
25 government to arrangements that are more horizontal in character and relatively
26 fragmented. In this context considerable scope emerges for the role of non-governmental
27 and philanthropic endeavour, often focused on single issues. Where this is combined
28 with high concentrations of individual wealth in the hands of elite donors – as was the
29 case in the USA from the 1980s – then the scope for private philanthropy to influence
30 the activities of the public domain becomes increasingly evident. Philanthropy may have
31 the potential to act as a transformative agent in this context and might engage in complex
32 areas of social and public interest that cut across the jurisdictions of specific departments
33 of government or particular service organizations. Much of the activity of the OSI can be
34 seen in this manner and the work of PDIA is a particularly good example of it.

35 This 'new' philanthropy, which can be distinguished from 'charity' that is oriented
36 primarily at the poor and at immediate needs, refers to something much wider in scope
37 than direct giving to good causes. This is private giving for explicitly public purposes with
38 a strong social ethic (Ostrower 1995). The philanthropic activities of George Soros fall
39 squarely into this domain, encompassing programmes for community development, as
40 well as for policy and legal change. They include advocacy and challenge to vested inter-
41 ests and at times have a strongly political character. PDIA fits into an emergent cadre of
42 New York based philanthropy that developed in the city from the 1980s. PDIA made a
43 contribution to the governance of death in the USA by highlighting the dimensions of





- 1 unrelieved suffering associated with dying and bereavement – and in turn creating the
2 conditions of possibility for their resolution.

3 Notes

- 4 ¹ Kathleen Foley interviewed by David Clark 22 July 2003.
5 ² Susan Block interviewed by David Clark 21 and 24 July 2003.
6 ³ For a listing of all PDIA grants, see www.soros.org/initiatives/pdia
7 ⁴ Susan Block presentation: PDIA Faculty Scholars Programme 1995-2004. Granlibakken, California,
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swapped
according to
alphabetical
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