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Pediatric Advocacy: Yesterday, Today, and Tomorrow

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Fig 1. Number of reported pertussis cases, by year—United States, 1997-2000.[1]

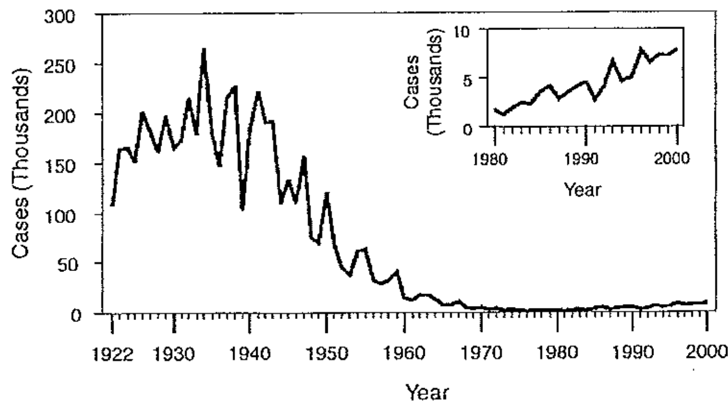

TABLE 1. Percent Distribution of Reported Pertussis by Age Groups in Three Time Periods[1,14]

Age Group (Years)	Massachusetts (1933–1939)	United States (1978–1981)	United States (1997–2000)
<1	7.5	53.5	29.4
1–4	41.1	26.5	11.1
5–9	46.0	8.2	9.8
10–14	4.1	5.4	
10–19			29.4
≥15	0.9	6.5	
≥20			20.4

have. This increased awareness of pertussis and experiences gained in the study of DTaP vaccines has led to better laboratory diagnosis of *B pertussis* infection. In general, *B pertussis* culture is now performed better, polymerase chain reaction is widely available, and adolescent and adult disease can be diagnosed by single-serum serology.

Pertussis will continue to be a problem until we address the epidemiology of *B pertussis*. The coming availability of dTaP vaccines for use in adolescents and adults and their universal use is the only solution to the "resurgent" pertussis problem.

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Pediatric Advocacy: Yesterday, Today, and Tomorrow

ABBREVIATIONS. AAP, American Academy of Pediatrics; APS, American Pediatric Society; AMA, American Medical Association.

The reason that advocacy is so much embedded in the work of pediatrics is that children have little political voice of their own and rely on the proxy voice of others including pediatricians to speak out on their behalf. This voice is so important because of the overrepresentation of our children among the poor and underserved. It should be stated that the "shared voice" of pediatrics has been heard throughout our history—speaking on behalf of all children.

As we proceed into the next millennium, it is proper to reflect on pediatrics' past, our present, and future so that, as a profession, advocacy will continue to play a key role. At the turn of the century, there were about a half dozen practitioners devoted to the care of children. Today, the membership of the

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American Academy of Pediatrics (AAP) is >57 000 physicians.

ABRAHAM JACOBI'S LEGACY: A TRADITION OF PEDIATRIC ADVOCACY

The role of advocacy in pediatrics dates back to the end of the 19th century when an epiphany within medicine crystallized the necessity that children deserved a cadre of professionals dedicated to their care. In addition, it was evident even then that an emphasis on advocacy and the protection of children would comprise a core aspect of the profession.

In the United States, Dr Abraham Jacobi is considered the "Father of Pediatrics." In 1859, he published his seminal text titled: *Midwifery and Diseases of Women and Children.* In addition, he was the first professor of pediatrics in America at New York Medical College, and in 1860 established the first free pediatric clinic in America.[1] Dr Jacobi was one of the pediatric pioneers who understood the link between the environmental milieu children found themselves and the incidence of disease. His efforts characterized the beneficence of our profession.

The emergence of the Industrial Revolution in the 19th century led to urbanization and a dismal state of public hygiene as we entered the 20th century. This was also the time of the "Great Wave of Immigration" when >25 million immigrants from southern and eastern Europe passed through the sanctuary of Ellis Island. One in 5 newborns did not survive to their fifth birthday, succumbing frequently to infantile diarrheal diseases resulting from contaminated milk. Eventually, milk stations providing pasteurized bottled milk in the 1920s augmented free clinics and dispensaries. This significantly reduced the infant and childhood mortality associated with diarrheal diseases.[2]

THE AAP: AN ORGANIZATION BORN OF ADVOCACY

The origins of the American Pediatric Society (APS) and the AAP also have their linkage with Abraham Jacobi. In 1880 Dr Jacobi organized the pediatric section of the American Medical Association (AMA) and was a founding member of the APS in 1888.[3]

In the early 20th century the pediatric section began to move away from the AMA because of philosophical differences on the need to advocate on behalf of women and children. The Sheppard-Towner and Infancy Protection Act of 1921 has been hailed as the first significant health care legislation in the United States. Its purpose was to reduce maternal and infant mortality rates in the United States by providing centers for prenatal and child health care. By 1922, 41 states provided instruction in maternal and infant hygiene.[4] The AMA, however, was not supportive. In 1922 the AMA House of Delegates condemned the Act for its presumed radical and socialist approach to medicine, despite the support of the pediatric section. With intense lobbying by the AMA, the law was eventually repealed in 1929 and by 1930 the pediatric section broke away because of the philosophical schism and strain to form the AAP.[3]

PEDIATRICS: A PROFESSION DEDICATED TO ACCESS FOR ALL CHILDREN

The commitment to expanding access to care for all children has been a theme that has accompanied the AAP and the vast majority of pediatricians over the past 70 years. Title XIX of the Social Security Amendments of 1965, or Medicaid, consolidated and expanded a number of smaller provisions of the Social Security Act. Medicaid marked the beginning of a new era in medical care for low-income families. In addition, the Early and Periodic Screening, Diagnosis, and Treatment program, passed in 1967, ensured a preventive arm to the Medicaid program.[5] Since the initial passage of Medicaid, the AAP has provided strong and persistent support in terms of expanding access to those most vulnerable and underserved. Throughout the 1980s and the early 1990s Congress passed a series of Medicaid eligibility provisions through a series of Omnibus Budget Reconciliation Bills raising the income thresholds and loosening the categorical requirements for uninsured families and their children.[6] In addition, it was the AAP with the grassroots support of pediatricians at the state level that eventually led to the passage of the Child Health Insurance Reform Program that required the provision of well-child and preventive services in private insurance coverage.[7] The program was conceived because as many as 58% of preschool children had not received the preventive care recommended by the AAP and the US Public Health Service.[8]

The Academy was instrumental with the passage of the State Child Health Insurance Plan or Title XIX of the Social Security Act in 1997, some 30 years after the passage of Medicaid.[9] Today, 5 years after its passage, the State Child Health Insurance Plan has extended health coverage to 4 million children and adolescents and we continue to advocate for universal health coverage for all children through the MediKids proposal.

PEDIATRICS TODAY: REFINING AN ADVOCACY AND POLICY PERSPECTIVE

The underpinning principle that runs throughout the history of pediatrics is the need to advocate on behalf of the children that we serve. Yet some pediatricians today still feel uncomfortable with the topic. There is a two-fold reason that health professional shy away from the discussion of advocacy and public policy. First, there is little familiarity with the body of literature on health services research, policy analysis, and system change in the present medical school and residency-training curriculum. It seems foreign and far-removed from the background, training, and professional experience of either academic medicine and/or clinical pediatrics. Second, there is a quick assumption that lobbying and advocacy are synonymous terms rather that lobbying being a small subset of policy and advocacy activities in general.

It is, therefore, apropos that the Accreditation

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TABLE 1. Advocacy Components of Pediatric Residency Training

- Community-oriented care with focus on health needs of all children within a community, particularly underserved populations
- The multicultural dimensions of health care
- Environmental toxicants and their effects on child health
- The role of the pediatrician within school and day care settings
- The role of pediatricians in the legislative process
- The role of the pediatrician in disease and injury prevention
- The role of the pediatrician in the regional emergency medical system for children

Council for Graduate Medical Education (the American Board of Pediatrics and its Residency Review Committee) have incorporated the following advocacy provision in the requirements for the pediatric resident in their community experience.

> "There must be a structured education experience that prepares residents for the role of advocate for the health of the children with the community."

Table 1 provides the pediatric residency requirements that have been operationalized into core curricular competencies.[10]

There are a plethora of definitions for advocacy. Tompkins et al[11] defined child advocacy as, "Child advocacy will be viewed as a process that seeks to champion the rights of all children and to make every child's needs known and met." A similar definition by Wolfenberger[12] states: "Advocacy involves the determination of a child's needs and the development of strategies to meet them." To effectively advocate on behalf of children one must think strategically and then understand the public policy process. Kingdon[13] provides the components of a policy framework for better understanding of the policy process. First, policy formulation requires that one is aware of the policy agenda and has an ability to propose policy solutions within the present political milieu. Second, policy implementation and evaluation reflects the need to monitor both intended and unintended outcomes. The final step is modification so as to strengthen and enhance the policy and thus the process starts over once again.

In addition, to be effective pediatricians need to develop an arsenal of tools similar to their clinical skills that will facilitate their advocacy activities. Table 2 provides a summary of an Advocacy Skills Tool Kit that is part of a curriculum taught at the University of Minnesota in a semester format titled: Advocacy Change for Children. The class is designed as a multidisciplinary seminar open across the Academic Health Center to graduate students in public health, public policy, nursing, and social work as well as medical students, residents, and pediatric and adolescent fellows. The major components include the advocacy skills listed in Table 2.

TABLE 2. The Pediatrician Advocacy Skill Tool Kit

- Letter to the editor
- An fact/advocacy sheet
- A political context analysis
- The building of a coalition strategy
- The utilization of a media strategy
- The development of an issue brief
- Written testimony

These advocacy skills will enhance a pediatrician's ability to effectively engage the public policy process by translating their clinical knowledge and expertise in a style and format that policymakers will find accessible. In addition, it they may be used with advocacy work in the public setting at all levels of government and in the private sector.

The "letter to the editor" is probably the first step taken by many. It consists of taking a prominent topic that is receiving some discussion and stepping forward to contribute your professional insights. The litany of topics from access to care, efficacy of immunization, and the importance of well-child care, are just a few of the topics that have health implications which need pediatrician input.

The "advocacy fact sheet" usually consists of a 1- to 2-page summary of a topic designed to get others interested in learning more on a topic. The task is to take the research findings that exist on an issue and to summarize succinctly the importance of the issue and why action is necessary to affect change. It frequently also encourages contacting their legislator in support of the proposal.

A "political context analysis" attempts to capture in no more than a few pages the present political milieu and an assessment of the fiscal and economic situation that a community, state, and/or federal government is dealing with. The purpose is to identify the top concerns of policymakers that may relate to, crowd out, or otherwise influence thinking on children's issues. How we advocate for change varies depending on whether we are in a growth economy such as much of the 1990s or a period of cyclical recessions that we see as part of the typical business cycle as characterized as the recession of 1981, 1991, or of 2003. The political context analysis is an internal needs assessment that is used by an organization in the development of the remainder of the "pediatrician's advocacy tool kit."

Developing a "coalition strategy" is an attempt to list the potential organizations pediatricians might want to try to convince to become coalition members and why they are needed as children advocates. In addition, it is important to identify unlikely supporters or opponents.

The "press release" should announce the unveiling of the coalition, the problem that has been identified, the recommendation being proposed, and where someone could get more information. In addition, the press release is part of an overall media strategy that should include a plan that visions out a 12- to 24-month approach on how the coalition will used the media to build public support for your proposal.

An "issue brief" is a stand-alone paper that can be shared as representing your organizations and/or coalitions perspective with either the legislative or executive branches of government at any level. It should assume that the reader is quite inexperienced on children's issues. This paper must be fair, but must also be persuasive and convincing regarding the argument for the proposal. The issue brief must

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be no more than 6 pages in length and single-spaced, including a 1-page executive summary. It should contain summary information on:

- The problem—background material that includes national and/or state experience with the issue in the last decade
- Suggested solution, including how you propose to finance it
- Evidence of scientific or experiential support for the suggested solution
- Pros and cons of the suggested solution
- Other possible policy options
- Arguments likely to come from opponents with possible answers to the opponents' arguments.
- An alternative or fall back position—if the initial attempt is not successful with the original proposal, what will be a proposal to keep the issue alive and build support for the coming year? Outline your strategy.

Finally, the "written testimony" provides the information extracted from all the above on what should be present personally if called to provide testimony at a legislative hearing or with an executive branch agency.

EPILOGUE: WHAT DOES THE FUTURE HOLD?

L. E. Holt Sr, in his remarks to the APS in 1923, stated: "If you today have a broader vision of your science than the men of 25 years ago it is not because your sight is better but because you stand on their shoulders."[14] We carry on in the advocacy tradition of Abraham Jacobi and L. E. Holt in the visualization that all children have the opportunity of reaching their fullest potential.

The recent Annie Dyson community grants provide an opportunity to explore and develop such skills. It should also be noted that the AAP through the annual legislative conference and advocacy forums continue to train a cadre of pediatricians in the importance of public policy and advocacy. In addition, the Committee on Federal Government Affairs and the Committee on State Government Affairs provide expertise, leadership, experience, and assistance to those chapters and individual pediatricians looking to make a change for children.

Finally, as always, the hope of pediatrics for the future is to improve the health and well-being of our children. Such skills will be necessary as we attempt to address the pressing issues of persistent health disparities, inadequate access to health care, limited dental and mental health services, environmental protection, and the promotion of a medical home for all children. This hope remains as relevant today as it was for our predecessors and serves as a beacon for the voyage into the 21st century.

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Racial Disparities in Renal Transplantation in Children

In an article in this month's issue, Drukker et al[1] from Jerusalem, Israel, are to be congratulated for writing a clear, precise, and provocative article concerning ethnic disparities in the selection of children for renal transplantation. Their article documents the remarkable finding that religious and ethnic biases do not affect access to transplantation in the midst of political upheaval. Their noteworthy article demonstrates that in Israel children are chosen for cadaveric renal transplantation regardless of ethnicity—(Israeli or Arab or religious status [Jewish, Muslim, Druse, or Christian faith]). This finding is reassuring not only to pediatric nephrologists, but to all physicians who care for children. The Jerusalem group deserves our admiration.

In the discussion, the authors make a comparison between children in Israel, where there exists equal access to cadaveric kidneys for Jewish and Arab children despite a tense political situation, and chil-

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