
PEDIATRIC ADVOCACY

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"Every physician is by destiny a 'political being' in the sense which the ancients defined the term, -viz., a citizen of a commonwealth, with many rights and great responsibilities. The latter grow with increased power, both physical and intellectual. The scientific attainments of the physician and his appreciation of the source of evil enable him to strike at its roots by advising aid and remedies."

ABRAHAM JACOBI, MD³⁵

The word *advocacy* is used in several different ways within the context of pediatrics. To paraphrase a dictionary definition of the term, advocacy is the act or process of pleading in favor of or supporting or recommending a cause or proposal.⁶⁷ Rudolph et al⁶¹ define a pediatric problem requiring advocacy as "any child health problem where the system is at fault and political action is required." To Christoffel,¹⁹ "[p]ublic health advocacy is advocacy that is intended to reduce death or disability in groups of people (overall or from a specific cause) and that is not confined to clinical settings." In the pediatric context, clinicians most often think about being an advocate for an individual patient. They recommend to parents that they immunize their children. They try to protect children who they suspect may have been abused physically, psychologically, or sexually. They intervene with insurance companies to get children services that they think children need.³⁹

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There is also advocacy on the larger scale. Pediatricians have a long history of working with their communities, with nongovernmental organizations (NGOs), and working at the interface between government, be it local, state, or federal, and the health sector.

This article reviews, briefly and superficially, some of the history of advocacy in pediatrics to set the context of the rest of the article and to document that advocacy activities are integral to pediatrics. This article also discusses how the reader can become more involved in larger-scale advocacy activities and focuses particularly on opportunities available in the realm of children's environmental health.

HISTORY

There is a long history of advocacy in pediatrics. The quote at the beginning of this article is from Jacobi, the first recognized leader of pediatrics in the United States.^{14, 25, 29} If the 19th century use of the male pronoun is ignored, Jacobi's sentiment is as true today as it was more than 100 years ago.

Jacobi's list of accomplishments as an advocate is long and exceedingly broad in scope.²⁹ He created the first milk station in the United States to provide boiled milk to avoid the biologic hazards of raw milk. He worked for birth control, the admission of women to The Johns Hopkins School of Medicine, and for the advancement of Native Americans and blacks.

The founding of the American Academy of Pediatrics (AAP) was based on an advocacy position taken by a group of pediatricians in support of federal legislation. In June 1922, the American Medical Association (AMA) House of Delegates passed a resolution condemning the Sheppard-Towner Act on the same day that the Section on Diseases of Children adopted a resolution approving the legislation. The Sheppard-Towner Act was the first piece of maternal and child health legislation passed by the US government. It provided federal matching funds to the states to devise educational programs and services for pregnant women and new mothers. The AMA House of Delegates responded by sending a committee to reprimand the Section on Diseases of Children. They reportedly were met with "unrepentance and jeers," and subsequently the AAP was formed. The specific leaders of the AMA Section on Children are unknown to the AAP.⁵³

Thousands of pediatricians worldwide are advocates for children. An exhaustive list of involved physicians is beyond the scope of this article, and the absence of any given individual is not for lack of appreciation of their efforts on behalf of children; however, discussing the work of some advocates provides ideas for the reader on how to begin or become a more effective advocate.

One of the contemporary exemplars of pediatric advocacy is Bergman, who has focused on a variety of issues over the past 3 decades. In the 1970s, he was a leader in the effort to obtain research funding for sudden infant death syndrome (SIDS). This effort required convincing physicians and scientists that SIDS is a medical syndrome worthy of study and it required convincing politicians to fund the research on SIDS.⁹ Bergman also has been involved in injury prevention research^{2, 11} and advocacy,¹⁰ advocacy for foster children,⁶⁸ improving the working situation for pediatric residents,¹² and in teaching others advocacy skills.⁴⁰

Within the field of injury prevention, a number of pediatrician activists have flourished. Sanders, a public health pediatrician in Tennessee, led the fight for the first seat restraint law in the United States: the prelude to seat restraint and seat belt laws now in force throughout the United States and in many foreign

countries.^{62, 63} Christoffel has spent 20 years doing research, writing, and speaking out forcefully about violence, specifically gun violence, as a medical and public health issue.^{20, 21} She is the founder and leader of the Handgun Epidemic Lowering Plan (HELP) Network, a US organization working to end the toll of morbidity and mortality associated with the free access to handguns in the United States.

Harvey has worked tirelessly to try to establish a universal health insurance system for children in the United States.³⁰⁻³³ He was able to use his positions in the hierarchy of the AAP, the strength of the organization, and its considerable lobbying capabilities to try to push this proposal forward. Unfortunately, not all good ideas succeed.

The range of pediatric advocacy activities is as broad as the range of the lives of children. Because children spend so much time in school and have so many needs within the educational systems in the United States, pediatricians have become involved. Palfrey has worked to document the needs of children in the school system and had tried to correct the deficiencies noted there.^{38, 50} She has worked to improve access to school and services within schools for children with special needs. She took on the controversial issue of teaching children with HIV infection and AIDS in the school system,⁵¹ and she has looked more broadly at the issue of health care reform and how it would need to be structured to help children with disabilities.⁵²

In the area of children's environmental health, there are and have been many pediatric advocates. All of the other authors in this issue of the *Pediatric Clinics of North America* have gone beyond their practices or their laboratories to educate the public, fellow health care providers, legislators, and government bureaucrats about the special needs of children in the context of environmental health. Each of their articles in this issue is part of that effort.

This author has not provided this roster of names of individuals who have long lists of publications in an attempt to intimidate anyone. Each of these individuals was inspired by an issue or a problem that she or he had noted, started small, and moved on from there; however, to be an advocate, the physician does not have to produce the research and publications of the people that the author has listed. There are many pediatricians working in their communities or with government bodies who synthesize the data collected by others, make them useful for nonmedical people, and advocate to improve the lives of children. Advocacy need not be a full-time job, and, like other skills in pediatrics, advocacy skills can be learned. Although the author has listed these pediatricians as individuals, none of them worked alone. They always worked with others within and outside of the health care profession.

WHY GET INVOLVED?

Physicians have been whipsawed by changes in educational, practice, and research circumstances over the past 50 years. In the area of practice, the predominant mode of operation has gone from a fee-for-service system to systems of negotiated fees or capitation. Some would argue that the fee-for-service system presented perverse incentives for physicians to see patients more often and do more tests and procedures to increase their own incomes. Others would argue that the current systems of negotiated fees or capitation have introduced the rules of the marketplace too strongly into the field of medicine and have eroded the patient-physician relationship and the professionalism of physicians. Soros⁶⁶ believes that "We must find ways that allow medical students and young

physicians to express the altruism and sense of service that brought some of them into medicine in the first place. At the same time, they must also be encouraged to learn the skills of advocacy."

When discussing pediatric advocacy, the author has heard residents say that politics is a dirty business controlled by money and that it is futile for pediatricians to become involved. The author suspects that sentiment is shared by many and is used as an excuse by many to avoid involvement in civil society; however, citizens have a participatory democracy that requires citizen involvement to function. Physicians must, because of their professional status, serve vulnerable populations and participate in the life of their communities. They must place the goals of individual and public health above the goals of personal or corporate wealth.⁷⁰ The privileges that society grants to health care professionals through direct and indirect subsidies of education, through privileged knowledge of peoples' lives, and through contact with their bodies that are forbidden to others require that they give back to society.⁴¹ Some would go so far as to say that such activities should be required for licensure and board certification.⁵⁹

McCally and Cassel⁴³ argue that physicians do have a responsibility to become involved in trying to minimize environmental degradation and improve the status of the global environment. These responsibilities derive from knowledge, which is not available to everyone, of the real and potential health effects of environmental degradation. In other aspects of practice (e.g., the management of obesity or diabetes), physicians work with patients and their families to try to modify their environment and behavior to improve their health. In addition, physicians have a broader social responsibility to protect the public's health. Hence, they report certain infectious diseases. This responsibility extends to the environmental areas as well. Although health care professionals have relatively little authority to control the sources of environmental risk, they can monitor the effects on patients and the community and advocate for risk reduction or risk elimination.¹⁶

SKILLS AND ATTRIBUTES

Although the author does not know whether anyone has studied the skills and attributes that are required to be successful at child advocacy, the following is an impressionistic appraisal based on the author's having worked on and off at the interface between children's health, community organizations, and state and federal governments for many years. Some of these skills and attributes are more concrete and learnable; some are more nebulous.

Honesty is the key to all advocacy. Advocates must have facts and must portray those facts in a truthful, straightforward manner. A physician advocate is only valuable to the extent that facts and ideas are not slanted to support the cause. Although it is important to be as objective as is humanly possible and to use the best evidence available in reaching conclusions and opinions, it is also important not to reject new or different ideas out of hand. Physicians can never be absolutely certain about anything,⁵⁷ but they can be certain enough to advocate for better environmental health for children.

Advocates must have or develop the ability to serve multiple constituencies simultaneously—self, family, patients, and the cause. The need for serving self and family first is not selfishness because they provide the basis from which all other work can be done. There is a distinct advantage for advocates to maintain clinical activities and responsibilities. These activities are a source of credibility

and a source of ideas and issues. The "cause" comes last unless the physician is a full-time advocate.

The advocate needs to have or develop what the author terms *critical curiosity*. This means that he or she must want to learn about issues and must be willing to critically evaluate incoming information. The advocate cannot accept information as valid just because it has been published. Others have written extensively on the assessment of information in the medical literature, and the reader is referred to that series of articles.^{28, 49}

In children's environmental health advocacy, information must be taken from the basic medical sciences, from clinical research, from writings as disparate as those in the air pollution or architectural literature, and from the policy literature and synthesize all this material into a coherent recommendation. One of the implications here is that an individual must be comfortable working at the interface between different parts of society, such as between medicine and government or between science and the community. The advocate needs to be comfortable being a "jack of many trades" without necessarily being the master of those many trades.

Participation in advocacy issues requires patience and persistence. It is rare that anything happens on the first try, and it is rare that anything happens exactly the way that it may be planned. For example, in the fall of 1999, the US Environmental Protection Agency asked many NGOs to provide input on the development of what was then called the Voluntary Children's Chemical Testing Program, a proposed program to gather information on the potential toxicity of chemicals. Over the course of 9 months, there were three major meetings and many smaller meetings. Representatives from the children's environmental health community, the chemical manufacturer's community, and the animal rights community made presentations about how they thought the program should be developed. More than 1 year after the original meeting, the name of the proposed program was changed to the Voluntary Children's Chemical Evaluation Program, and an outline of the proposal was published in the *Federal Register*. It will be at least July 2001 before it is known whether this program actually will begin to function.

Patience and persistence are also important because, win or lose, when it is over, it really is not over. After a law is passed, regulations must be written. Those unhappy with the law will try to influence how the regulations are written to change something in the direction that they favor. Alternatively, after a law is written to create a program, its detractors may try to block the funding for the program, or try, in some subsequent legislative session, to get the law repealed or "improved." If all else fails, opponents can go to court to try to get the law declared unconstitutional or for the court to order the executive branch to do something that they believe it should be, but is not, doing.

All physicians are teachers of their patients and sometimes of others as well. This skill is essential for an advocate. All physicians are advocates at that one-on-one level. When working at the community or national levels, the advocate needs to be facile with the written and spoken word. He or she also needs to take care that these skills do not lead to a loss of honesty or clarity. It is important to keep in mind that the average citizen in the United States reads at a sixth grade level.

Part of reaching out to the public is communication with and through the media. Reporters need background information so that they can understand complex medical and scientific issues. They then need information that can be communicated to the public.⁶⁰ Many organizations, such as the AAP, sponsor opportunities for media training for pediatricians.

A lot of advocacy is telling people that one idea is better or worse than another. Therefore, developing skills in risk assessment and risk communication can be useful. As advocates ask the public to make decisions about environmental issues, they need to be able to understand and weigh the risks that the advocates are describing. It is incumbent to understand those risks (risk assessment) and to arouse the appropriate level of concern without creating complacency or panic.^{42, 48, 58}

Coalition building is an important skill. Advocates usually can be more effective if they can convince others to work with them and if they can convince organizations to support their position. Coalitions also help get the message out more broadly. There are logical allies in the community with whom pediatric health care providers can forge bonds. These may include teachers, lawyers, public health officials, school nurses, and others. Local religious groups and local parent-teacher associations often are involved in activities related to environmental health.

Developing skills in epidemiology, biostatistics, and some of the other "basic sciences" of public health can be helpful to advocacy work. Epidemiologic information is not sufficient for making policy decisions, however. Often, advocacy positions need to be taken and public health decisions need to be made in the face of incomplete evidence. There will never be complete information.^{8, 64} (See subsequent discussion of precautionary principle.)

HOW TO GET INVOLVED

There are many ways to receive training in advocacy skills. At the medical student level, the American Medical Student Association sponsors the Washington Health Policy Fellowship Program.⁶ Students come to Washington, DC, receive training, and then work in congressional offices, federal agencies, research institutes, or health advocacy organizations. The Medicine as a Profession Program of the Open Society Institute of the Soros Foundation sponsors the Soros Service Program for Community Health: "The Program aims to foster a commitment to service to the community and advocacy on behalf of vulnerable populations among medical students and young professionals."⁶⁶

As a result of requirements of the Pediatric Residency Review Committee of the Accreditation Council on Graduate Medical Education, residency programs are making advocacy activities part of their training.¹ For example, Children's National Medical Center in Washington, DC has developed the Robert Parrott REACH program. This program will allow one half-day per week for second- and third-year residents to work on projects in research, education, advocacy, or child health care.¹⁸

The AAP sponsors a Legislative Conference.⁴ The participants have an opportunity to learn about the legislative process and participate in mock visits to congressional offices and mock hearings. They then visit individual members of the US House of Representatives and the Senate to advocate for selected policy positions. The AAP also publishes a *Government Affairs Handbook*,⁵ which contains excellent information for child advocates working at the local, state, and federal levels.

Pediatricians can obtain additional training through a Masters of Public Health degree. With training in epidemiology and biostatistics, the pediatrician develops data analysis skills. Potential advocates also can study the structure and function of the legislative and executive branches of government and the responsibilities of individual executive branch agencies.

Fellowship programs are another way to garner additional experience in advocacy. Over the past 28 years, a number of pediatricians have participated in the Robert Wood Johnson Health Policy Fellowship Program managed by the Institute of Medicine of the National Academies of Sciences.^{27, 34, 44, 46} This program brings six midcareer health care professionals to Washington, DC every year, gives them an intensive 3-month orientation, and then sends them to work in Congress or the Executive Branch of the federal government.

The Medicine as a Profession Program of the Open Society Institute of the Soros Foundation sponsors the Soros Advocacy Fellowship Program for Physicians. The purpose of this program is "to inspire the [medical] profession to greater participation in civil society, service to the community, and active engagement on behalf of the public interest." The Soros Advocacy Fellows work with NGOs at the local, state, regional, or national levels.⁶⁶

To date Soros Advocacy Fellows are pursuing such projects as:

- Collaborating with a national advocacy organization to increase opportunities for medical professionals to become actively engaged in children's environmental health policy.
- Partnering with a state advocacy organization to assess the health needs of recent Hispanic immigrants to increase their access to health care and to improve the quality of care.
- Working with the state chapter of a national advocacy organization to promote training in emergency contraception and medical abortions for those entering family medicine.

Several authors have tried to describe the process of becoming an effective child advocate^{13, 19} and the process of effecting change in public policy.⁸ Initially the advocate must gather quantitative and qualitative information about all facets of the controversy; however, information alone is never sufficient to change public policy. There must be a political will and a social strategy. The advocate must go into the community, participate in community organizations, and develop a network of contacts. He or she then must develop an understanding of the legislative or regulatory processes. Advocates can read about the process, but like so many other things in medicine, the best education about the legislative and regulatory processes comes from participating in them. Advocates can develop linkages with someone who knows the process and work with that individual to pass or block legislation or to influence the development of a regulation. This method is also the way to learn strategy and coalition building. It is also during this phase that communications skills can be honed. There are times when it also may be important to be involved in litigation, and it is always important to remember to monitor the implementation of the policy over the long haul. Having derived this knowledge and experience, the pediatrician can begin to take a leadership role in advocacy activities and organizations. Once the process is learned, it can be implemented:

- Develop a clear mission
- Implement a strategy of small wins
- Identify friends and build coalitions
- Identify adversaries and attempt to neutralize their opposition
- Be pragmatic and willing to compromise
- Don't burn bridges and never compromise a legislator
- Hire an effective lobbyist
- Develop a good working relationship with the media (newspaper, radio and television)
- To the extent possible, minimize looking self-serving

The process of public health advocacy is not linear; it is iterative. Moreover, the process is not unifocal; if it is to be successful, it needs to be multifocal.⁶⁵ Erdmann et al,²² in their discussion of the success of the effort to lower hot water heater temperatures in Washington State, point to the importance of the law, public education, and time.

There are many opportunities for personal involvement in environmental advocacy activities. The Resource Guide¹⁷ created by the Children's Environmental Health Network lists hundreds of local and national organizations involved in children's environmental health activities. One of the most important things that a pediatrician could do is to become involved directly in the activities of one of these organizations. There are hundreds of local and regional organizations that have a crying need for expertise in health issues. The pediatrician could provide that expertise. State chapters of the AAP have formed, or are forming, committees on environmental health, and the AAP has a national committee on environmental health.³ Physicians for Social Responsibility (PSR) also has committees on environmental health at the national level and within its various chapters.⁵⁴ PSR frequently needs volunteers to participate in local or regional activities designed to increase public awareness about air pollution, water pollution, global warming, or other topics.

The work of one individual is rarely sufficient to have a new idea or policy accepted. It usually takes a coalition of individuals and groups, and it takes a multifaceted approach involving public education and education of key decision makers, such as members of the press, clergy, and elected officials. In addition, legislation, regulation, and litigation all are required sometimes. The decrease in tobacco use or the increase in seat belt and seat restraint use could not have been achieved with more limited approaches.^{7, 36, 37}

Finally, pediatricians can participate in a limited but important way by supporting one or more of these organizations financially. Monetary support allows these organizations to achieve goals by paying for staff, mailings, and other activities.

Early in the advocacy process, the "answers," whether they are about tobacco smoke or persistent organic pollutants or climate change, are rarely evident. Pediatricians can wait for more data to accrue and, therefore, not advocate for change, or they can take a precautionary approach. The term *precautionary principle*⁵⁶ has been developed to describe this latter approach. Summarized into a sentence, it states, "When an activity raises threats of harm to the environment or human health, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically." Clearly, such a statement is open to wide interpretation, and the precautionary principle has been controversial.^{24, 26, 55} However, in medicine in general and pediatrics in particular, clinicians firmly adhere to the precautionary principle. The phrase *primum non nocere* is one of the first that health care providers learn in clinical medicine.

Clinicians also know that in many other areas of medicine providers act without full information. For example, many drugs have not been tested fully in children, yet physicians use them. The National Institutes of Health has created a consensus development process to help health care providers, patients, and the public deal with complex medical issues when the answers may not be entirely clear.^{23, 47, 69}

BARRIERS

There are clearly a number of barriers to being a pediatrician-advocate. First, and perhaps foremost, pediatricians are trained to be clinicians. Direct

patient care is rewarding and the rewards are immediate. The smile of the parent and sometimes the patient after most encounters makes the physician feel good. The work of advocacy is more long term, and the rewards, if any, are delayed. Advocacy is clearly time consuming and, as a result, can have an adverse effect on patient care and relationships with colleagues in the office. Being an advocate can embroil a practitioner in controversies that are not of his or her own making. This issue too has the potential to have an adverse impact on practice.

Further, pediatricians have little training in children's environmental health in medical school (an average of 6 hours for all environmental health training)¹⁵ or residency. Although there are a few fellowships in toxicology or other related fields, until the summer of 2002, there will have been no fellowships in children's environmental health.

Making the diagnosis of environmental injury in an individual patient is difficult. Traditional toxicologic data generally look at exposures to single chemicals at relatively high doses. Many real-world situations involve long-term, low-dose exposures to single or multiple entities. With the exception of lead and a few other chemicals, there are relatively little data on the outcome of these situations.

SUMMARY

Advocacy is part of the job description of a pediatrician. There is a long history of pediatrician involvement in civil society. Like other skills in pediatrics, the skills required for advocacy activities are learnable. Anyone who can learn the Krebs cycle can learn how to be a child advocate. Being a child advocate is not always easy, but it is rewarding.

The 1995 Nobel Prize in Chemistry was awarded to Rowland et al for their work in the description of the destruction of stratospheric ozone by chlorofluorocarbons. Having done the groundbreaking research,⁴⁵ Rowland and Molina spent much time working to ban chlorofluorocarbons. When asked why they, as bench scientists, ventured out of the laboratory as advocates, Rowland stated, "If not me, who? If not now, when?" (personal communication, December 7, 2000).

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