Citizen Rights and State Responses

Legal and Public Policy Responses of States to Bioterrorism

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In late 2001, during the aftermath of the anthrax letter attacks, model legislation was proposed to relevant state agencies to update their states' public health laws to meet the threat of bioterrorism. This legislation was the Model State Emergency Health Powers Act.

A concern underlying this and related efforts to address future bioterrorism threats was the perceived inadequacy of state laws to respond effectively when such threats occur. We evaluated how 4 states—Utah, Maine, South Dakota, and Indiana—addressed this concern in the context of the model legislation.

The conclusion is that the model legislation generally served as an important catalyst for state action in the field of bioterrorism preparation. (*Am J Public Health.* 2004;94:1093–1096)

THE ANTHRAX ATTACKS IN the fall of 2001 raised the question of whether each level of government in the United States had adequate authority and resources to respond to future attacks. In the US defense against bioterrorism, state and local agencies will most likely be on the front lines because these levels have the primary responsibility for public health.[1] The Center for Law and the Public's Health at Georgetown and Johns Hopkins universities wrote model legislation for states seeking to update their laws relating to public health emergencies because these laws are arguably outdated.[2] The Model State Emergency Health Powers Act (MSEHPA) highlights those powers the center found should be granted to states to detect and respond sufficiently to future bioterrorist attacks.

States received copies of the MSEHPA in late 2001, and many initiated legislative or administrative efforts to adopt part or all of its text.[3] This study examines how 4 states—Utah, Maine, South Dakota, and Indiana—interpreted the MSEHPA to try to achieve the goals of effective bioterrorism detection and response. These states are in different regions of the country, and they addressed the challenges presented by the threat of bioterrorism differently. The general conclusion of this article is that the MSEHPA usually served as a catalyst for health care providers, law enforcement personnel, political leaders, and citizens at large to discuss how to improve their public health laws.

THE SUBSTANCE OF THE MSEHPA

The MSEHPA has 2 broad operational goals relevant to infectious disease—effective detection of the problem and effective response.[4] In terms of detection, the MSEHPA places pharmacies, hospitals, and outpatient service providers on the front lines against bioterrorism. Before the MSEHPA, many states prevented private businesses like pharmacies from sharing information with health authorities and prohibited health authorities from sharing information with state police. The MSEHPA requires pharmacists who notice peculiar increases in specific medicines to contact state or local health authorities. If public health officials think it necessary, the pharmacist is even required to supply names and addresses of specific individuals. When public health authorities learn of a case they "reasonably believe" to be the result of bioterrorism, the MSEHPA directs them to inform public safety authorities immediately.

Once public health authorities detect a possible bioterrorist attack, they must then develop an effective response to the emergency. Under article II of the MSEHPA, states should already have coordinated their response measures to public health emergencies. After a governor declares a public health emergency, she may suspend any regulatory statute if strict compliance with such laws would "prevent, hinder or delay necessary action" to respond to the threat. The public health authorities coordinate the state's response to the emergency, and the state legislature can terminate the state of public health emergency at any point.

One potentially controversial response measure is the isolation and quarantine of potentially infected individuals.[5] The MSEHPA gives the state broad power to do so, on the condition that isolation and quarantine are the "least restrictive means" to prevent the spread of infectious disease. Failure to abide by the state's directions in isolation or quarantine would constitute a misdemeanor. Additional response measures include mandatory vaccinations, and seizure of private property. At the same time, the MSEHPA guarantees affected individuals some due process to demand release from isolation or quarantine. Specifically, individuals can request a court hearing for the state to show cause for the isolation or quarantine or for affected individuals to argue that the state

has breached conditions of the isolation or quarantine order.

Perhaps the foundational achievement of the MSEHPA is its articulation of how to balance social goals served by police powers with individual freedom. Absent such ex ante articulation, the state may quickly lose credibility and public trust after a bioterrorist attack and thus complicate efforts to mitigate the spread of infectious disease. For example, local officials in Muncie, Indiana, did not effectively communicate with citizens during a smallpox outbreak in 1893. Local officials sought quarantines, isolations, seizure of property, and mandatory vaccinations, but soon confronted violent resistance. More recently, the spread of severe acute respiratory syndrome (SARS) and the Chinese government's response to the disease likely diminished public trust in that government.[6] These experiences should encourage government leaders at all levels to discuss and develop effective detection and response strategies for bioterrorist and nonterrorist occurrences of infectious disease.

CASE STUDIES

The 4 states evaluated in this article present a useful comparison of how different states approach the same problem of the threat of bioterrorism. The Utah legislature addressed only detection issues, given the pressing need to prepare for the 2002 Winter Olympics in Salt Lake City. Maine largely ignored detection and focused instead on strengthening response powers. South Dakota also focused primarily on response in addition to clarifying jurisdictional issues between the state and county departments of health. Finally, confident in existing state powers to handle bioterrorist attacks, Indiana did not reform its public health laws.

Utah

After receiving the MSEHPA in late fall of 2001, Utah Department of Health officials decided to propose some reforms of the state's public health laws. However, it was an open question whether the agency should pursue a comprehensive—yet lengthy and time-consuming—set of reforms or a more modest version. Although the state might have benefited from both detection and response reforms, Utah health officials ultimately pursued only detection reforms for 2 reasons. First, the agency had already missed the deadline for submitting bills to the legislature for its 2002 session. As a result, the agency was more dependent than usual on individual legislators to draft and promote legislation, and a comprehensive set of reforms would likely have been too ambitious an undertaking. The agency could either have waited for almost a year to submit a comprehensive version or support a more modest version immediately. Second, the Winter Olympics in February 2002 strongly encouraged officials to choose the latter. It was deemed better to have a partial set of reforms in place before this potential terrorist target than nothing.

Utah's reforms focused on health care providers' expedited reporting of relevant information and the appropriate dissemination of that information. Preexisting state law mandated that physicians, pharmacists, and hospitals immediately report selected diagnoses to public health officials. However, "immediate reporting" could take as long as 14 days after a diagnosis. Waiting for a firm diagnosis before reporting the patient's conditions to public health authorities could worsen the bioterrorism attack's potential impact.[7] In addition to the mandatory reporting of diagnosed conditions, the changes authorized the voluntary reporting of syndromes and conditions. For example, pharmacists could report to the Department of Health that they had received an unusual number of requests for over-the-counter drugs. In addition, Utah followed the MSEHPA by authorizing public health officials to share information with law enforcement agencies.

Yet, the Department of Health and its allies in the legislature made several concessions to opponents. Originally, the department sought mandatory reporting conditions and syndromes. After several hospitals, pharmacists, and the Utah Medical Association argued that such extensive reporting requirements might pose serious administrative burdens on health care providers, the department agreed to the mandatory/voluntary distinction described previously. In response to concerns about individual privacy, the bill included a 2-year sunset provision and a clause mandating that the department must destroy any personal information within 180 days of its collection.

In the end, Utah did not change its quarantine laws or other response measures as part of this effort. The legislature had recently reformed these laws to help the Department of Health address cases of recalcitrant patients with tuberculosis or other infectious diseases. However, the new laws refer only to individuals, not groups, so it is unclear whether the Utah Department of Health has the full extent of quarantine authority envisioned in the MSEHPA. In terms of due process, the state is required to give quarantined individuals a hearing to determine the necessity of continuing such conditions within 10 business days. It is uncertain whether the state has the legal authority to mandate vaccinations for uncooperative individuals.

Maine

Unlike Utah, Maine focused primarily on bioterrorism response instead of detection. Maine already had some emergency powers, such as holding individuals for up to 48 hours for "public health purposes." A court could order such holding even if the individual did not come to court. However, the legislature considered these powers inadequate to respond to a bioterrorist attack.

Maine accorded its public health department new powers that would come into effect only after the governor declared an "extreme public health emer-

gency." Powers granted to the public health department included taking "a person into custody and order[ing] prescribed care."[8] The term *prescribed care* was defined broadly to include isolation, quarantine, mandatory vaccination, and medical examination and treatment ordered by the department. This covers many of the "response" powers detailed in the MSEHPA, including controversial issues like mandatory vaccinations. Yet, Maine sought to balance a need for public protection with respect for individual rights. For example, although the MSEHPA allows 10 days of quarantine and isolation before the affected individual receives a hearing, Maine authorized only 48 hours before such judicial intervention. In addition, Maine's law did not include the sections of the MSEHPA detailing how the state can handle the remains of infected or possibly infected individuals.

The Maine legislature did not address most detection issues to the extent envisioned in the MSEHPA. Maine law protecting personal health information would likely have conflicted with certain provisions in the MSEHPA. Specifically, legislators feared that a proposal to grant public health officials unrestricted access to individual-level health information regardless of the circumstances would encounter stiff political opposition. Instead, Maine allowed disclosure for the purpose of "protect[ing] the public health and welfare," which could be interpreted as allowing health care providers to share information in aggregate form. In addition, after declaration of an extreme public health emergency, the public health department can demand individual-level information related to that emergency.

Despite these changes, some concerns remain regarding the capacity of the public health system in Maine to respond to any attack. In particular, Maine may have insufficient institutional capacity to handle such public health emergencies. Maine has no county public health departments, and the state's 2002 application for Centers for Disease Control and Prevention (CDC) funds to augment the state's bioterrorism response capabilities pointed to a Department of Justice/CDC survey indicating that "immediate attention" was needed in 49 of the 88 key public health essential service dimensions.[9] This illustrates the need for many states to go beyond making only legal changes in enhancing community preparedness for bioterrorism and other public health emergencies.

South Dakota

The South Dakota legislature passed 2 bills in 2002 giving the governor several new powers to respond to bioterrorist attacks. One set of powers would come into effect after any "disaster, war, act of terrorism as defined by state law, or emergency that is beyond local government capability."[10] One of these powers is the governor's ability to "procure, acquire, store, distribute and dispense" pharmaceutical agents within the state's borders to respond to the event in question. This language is broader than the text of the MSEHPA, which would allow such actions only in times of a "shortage or threatened shortage" of pharmaceutical agents. Another key provision of the law is the ability of the governor to "appoint . . . out-of-state health care providers"[11] to respond to bioterrorist attacks, presumably in case the local supply of such providers appears insufficient. This language derives from the MSEHPA, which specifies how long providers may be licensed and their liability protections for civil damages.

One overarching change is the clarification of the South Dakota Department of Health's authority after the declaration of a public health emergency. Legislators and public health officials feared that time-consuming disputes between state and county health officials over each level's powers would occur. The legislature amended South Dakota laws relating to the emergency powers of both levels of the public health infrastructure and declared that the state shall have the "primary jurisdiction, responsibility, and authority for responding to a public health emergency."[12] Yet, there are some areas the South Dakota bills do not address. Specifically, state law already mandated reporting infectious diseases such as tuberculosis, and legislators did not seek to grant the state power to mandate vaccinations of individuals.

Indiana

Although many states reformed their laws regarding public health emergencies to detect or better respond to bioterrorist attacks, the Indiana legislature and public health officials believed they already had enough authority to respond to these situations. The Indiana legislature had already sought to balance the individual's interest in keeping health information confidential with the state's need to detect emerging infectious diseases quickly, regardless of whether these diseases were part of a bioterrorist attack. Usually, under Indiana state law, individual health information is confidential, and any person who violates this confidentiality is guilty of a misdemeanor. However, physicians and hospitals must report certain communicable disease information to the health department, and the department may track this information to respond effectively to these public health threats. These provisions may provide an adequate foundation for the detection of a bioterrorist attack, but the state could still reform its existing law and bolster improvements in public health. For example, Indiana could take steps similar to Utah's in monitoring the frequency with which health care providers actually report communicable diseases.

In terms of response, Indiana law grants significant emergency power to the public health commissioner, not the governor. In particular, the commissioner has the right to "establish quarantine[s] and may do what is reasonable and necessary for the prevention and suppression of disease." Another broad power granted to the commissioner is the "right to issue an order condemning or abating conditions

causative of disease."[13] Unlike the MSEHPA, Indiana law does not specify what due process a quarantined individual has.

CONCLUSION

All the states in this study considered the MSEHPA, but each eventually approached concerns about bioterrorism differently. Multiple factors—including the states' political dynamics, social characteristics, and existing legal frameworks—likely shaped these approaches. Although these states did not provide the consistency sought by the Center for Law and the Public's Health, their efforts still addressed some critical needs regarding bioterrorism detection and response.[14]

Study of this issue sheds light on the interaction between law and public policy in solving a complex and contemporary national, state, and local problem—bioterrorist attacks on civilian populations. Consistent and clarified law that minimizes time-consuming lawsuits in the event of a crisis is 1 aspect of a solution to this problem. Building on efforts to update their laws, states and localities should now direct their attention, other aspects—including funding and personnel.[15] ■

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Ethical Challenges in Preparing for Bioterrorism: Barriers Within the Health Care System

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Preparedness for bioterrorism poses significant ethical challenges. Although public health ethics and preparedness have received attention recently, health care ethics must also be considered.

In epidemics, the health care system assists public health in 3 tasks: detection, containment, and treatment. Detection might fail if all patients do not have access to care, or if physicians do not understand their obligation to report infectious diseases to public health authorities. Containment might fail if physicians view themselves only as advocates for individual patients, ignoring their social obligations as health professionals. Treatment might fail if physicians do not accept their professional duty to treat patients during epidemics.

Each of these potential ethical barriers to preparedness must be addressed by physicians and society. (*Am J Public Health.* 2004;94:1096–1102)

THE INTENTIONAL DISPERSAL of anthrax spores in the United States demonstrates the need for preparedness for bioterrorism, and the recent outbreak of severe acute respiratory syndrome (SARS) has renewed fears of unintentional or naturally occurring infectious epidemics. In responding to these threats, the public health system has rightfully garnered much of the attention,[1] after decades in which government has starved public health agencies of needed resources.[2–4] However, an effective response also will require the health care system to fulfill critical roles. By the term *health care system*, we mean those professionals (e.g., physicians and nurses) and institutions (e.g., hospitals and health plans) obliged to diagnose, treat, and care for individuals exposed to or infected with contagious diseases. We specify *contagious* diseases because although anthrax is not transmissible from person to person, many experts reserve their deepest fears for transmissible agents such as smallpox, plague, hemorrhagic fevers (e.g., the Ebola, Marburg, Lassa, and Crimean-Congo hemorrhagic fever viruses), and new (e.g., SARS) or designer viruses and bacteria.[5]

Thinking systematically, what are the obligations of the health care system in handling contagious diseases? The health care system should rapidly identify threats, help to prevent the spread of disease in the population, and care for infected patients. These 3 tasks—detection, containment, and treatment—are vital to the efficient handling of contagious epidemics. To prepare for each task, policymakers have emphasized training,[6–9] clarification of public health quarantine powers,[10,11] facilities improvements, and pharmaceutical stockpiling.[12–14] Although these steps are important, we wish to draw attention to several challenges related to medical ethics and professionalism that might hinder detection, containment, and treatment and that have been much less discussed. Ours is not an exhaustive compilation of the many ethical issues associated with bioterrorism, but the issues we raise have received relatively little attention recently and are at risk of being lost in the highly publicized debates over, for example, the ethics of smallpox vaccination. These issues also illustrate that contagious diseases raise critical questions about the ethical relationship between medicine and public health.[15]

DETECTION: REPORTING AND ACCESS TO CARE

In some bioterror scenarios, such as an aerosol release into a crowd, simultaneous widespread infections would mark an attack; if this were the case, then limiting the outbreak through early detection might provide little benefit (though early recognition and treatment of the illness might still save lives). But smaller-scale attacks are potentially much easier for terrorist organizations to organize, finance, and carry out.[16] As the anthrax mailings of October 2001 demonstrated, even relatively small attacks can provoke widespread anxiety and disruption. In a stealth attack, early detection becomes critically important, as it is in stemming naturally occurring outbreaks.

To improve detection, the United States is expanding the public health system's capacity for surveillance. However, public health surveillance relies largely on reports from health care professionals. Persons with symptoms arrive first in physicians' offices, clinics, or hospital emergency departments. For this system to work, therefore, patients must first have access to the health care system, and their illnesses must then be reported to the public health system.

The health care system must improve its reporting performance. Many physicians are unaware of reporting requirements, complain of the administrative burden of reporting, do not see reporting as important to patient care, or are unconvinced that reporting is of value.[17] Reporting must be made easier (or even automatic, through electronic links), and physicians should be given feedback on how their reports are used to safeguard public health, reinforcing the value of the physician–public health partnership. Examination of the physician's role in reporting contagious illnesses should be included in new curricula on professionalism[18] in the context of exploring the social roles of the medical profession—an issue to which we will return.

In the area of patient access to health care, more challenging dilemmas arise. Strong ethical reasons have long been recognized as supporting universal access to a decent minimal set of health care services,[19] yet our nation has been unable or unwilling to accomplish this.[20] Perhaps if policymakers understand that inadequate access to care poses a threat to national security, progress can be made.[21,22] In the United States, more than 40 million Americans lack health insurance, and this number is rising.[23,24] Although some uninsured individuals use emergency rooms to obtain care when they are acutely ill, many of the uninsured and underinsured avoid the health care system for as long as possible.[20] Some have argued that bioterror-related illnesses are so severe that anyone affected would surely seek care.[25] But uninsured patients discriminate poorly between appropriate and inappropriate care and tend to avoid both equally.[26] Numerous studies demonstrate that the uninsured are more likely to present in an advanced stage of illness, and many die without ever being evaluated.[27–29]

Terrorists undoubtedly recognize that even a small-scale release of an infectious agent into a community with a high rate of uninsurance might be devastatingly effective. Because most of the uninsured are employed and working throughout cities, suburbs, and rural areas, starting an outbreak in such a community—using a low-tech approach, such as an infected "martyr"—would reduce the likelihood of early detection and raise the odds of broad spread of the disease.[30] Unfortunately, this scenario is not mere speculation: "natural experiments" that simulate such an attack have demonstrated the vulnerability of poor, especially uninsured immigrant, populations and their ability to spread disease throughout the population.[31,32] Many naturally occurring infectious diseases, including tuberculosis, food-borne illnesses, and HIV/AIDS, disproportionately burden the uninsured and

subsequently spread to the community at large.[33]

Maintaining barriers to accessing health care in the face of today's threats should be unacceptable, morally and politically. In the aftermath of the September 11 attacks, New York ordered its health care system to provide care to all possible victims[34] and the state health commissioner, Antonio Coello Novello, declared to providers: "Thou shalt not ask who will pay for this."[35] Over the next 4 months, New York's special Disaster Relief Medicaid program enrolled and cared for almost 400 000 people.[36] New York dramatically streamlined the application process for Medicaid and obtained additional funding for the state pool for the uninsured. The public, government, and the medical community widely approved these actions as appropriate, given the threat.[37,38]

Learning from this experience, federal and state officials should make clear that individuals with symptoms that suggest infection with a contagious illness should present for evaluation and ensure that those who do can be treated without prejudice. Funding must be provided to cover screening and treatment of patients with contagious illnesses; in particular, funding for hospital emergency departments that see large volumes of uninsured patients must be increased.[39] Because patients cannot be expected to know in advance whether their illness is infectious, programs can be targeted toward contagious illness but ultimately, they will need to be broad based. Finally, funding alone might not guarantee ready access to care for certain populations, especially recent immigrants and those who mistrust the health care system.[22] The current policy focus on addressing racial and ethnic health disparities should be used to build a culturally sensitive primary care system in which all patients feel welcome.[40]

CONTAINMENT: ISOLATION BEFORE QUARANTINE

In late October 2001, the secretary of the US Department of Health and Human Services asked the states to increase their legal preparedness for potential epidemics.[41] Twenty-two states and the District of Columbia have since enacted laws based on the Model State Emergency Health Powers Act, drafted by the Center for Law and the Public's Health at the request of the Centers for Disease Control and Prevention.[42,43] These laws seek to ensure that when facing a clear emergency, the public health system can carry out screening, vaccination, quarantine, and treatment.[44] Even with these powers, however, the public health system cannot contain an outbreak as rapidly as might health care professionals who are willing and empowered to use short-term involuntary isolation when needed.

Of course, most contagious patients will comply voluntarily with an isolation request; but recent bioterror training scenarios assume that not everyone will cooperate with treatment and quarantines,[45,46] and this assumption is borne out in experiences with SARS.[47–49] Illness and fear can hinder clear thinking. Physicians should know this and be prepared to intervene if necessary. Under what legal authority might health care professionals isolate a potentially contagious patient *in advance* of a public health quarantine? Health care professionals have a general obligation to prevent patients from harming themselves or others and may use compulsion when necessary.[50] The most common application of this power might be to "hold" psychiatric patients thought to pose a suicide or homicide risk.[51] Such short-term physician holds usually require judicial review within 24 to 48 hours, but this kind of short-term legal authority could serve as an early stop to an outbreak in the event that one or more patients decline necessary interventions before the public health authority enforces quarantine.

In general, public health officers, not one's physician, should declare quarantine, because separation of these roles allows physicians to attend to individual patients' interests. Indeed, using professional powers to hold patients involuntarily poses a fundamental ethical challenge for physicians, because it entails overriding an individual patient's wishes in deference to the community's needs—balancing respect for patient autonomy against public health benefit. Challenging though it may be, however, mediating the tension between individual and community needs is integral to the role of the medical profession in society—and demonstrates why the profession must maintain some independence from both the state and patient interests.[52]

There are significant risks in physicians' acting as agents of the state,[53–55] yet attention to civic obligations is as ancient a part of professionalism as is attention to patients' interests. Plato bluntly recognized this balancing act when he wrote that physicians are "statesmen" who are to do what "is best for the patients *and* for the state."[56(p6)] More recently, Creuss and Creuss noted that during the 19th century

> legal measures for the first time granted medicine a broad monopoly over health care—along with both individual and collective autonomy—with the clear understanding that in return medicine would concern itself with the health problems of the society it served and would place the welfare of society above its own.[57(p943)]

The original 1847 Code of Medical Ethics of the American Medical Association noted that a physician's skills "are qualities which he holds in trust for the general good,"[58(p318)] and one of its 3 chapters—entitled, "Of the Duties of the Profession to the Public, and of the Obligations of the Public to the Profession"—dealt explicitly with physicians' social duties.[58(p333)]

In the era after 1955, however, medicine began to move away from balancing social obligations, tilting toward a more restricted advocacy position.[59,60] Obligations regarding public health were minimized, and physicians were eventually urged to ignore civic considerations altogether and to think only of the welfare of the patient before them. In 1984, Norman Levinsky wrote that “physicians are required to do everything that they believe may benefit each patient, without regard to costs or other societal considerations.”[61(p1574)] This statement reflected the domination of medical ethics by respect for patient autonomy and the loss of a cardinal feature of professionalism: mediation between private and community interests.[53,62] But, bereft of its role as a social protector, medicine was left with only technical expertise to support its claims to professional prerogatives, which are granted by society and have since steadily eroded.[63,64] Recognizing this chain of events, recent scholars of the medical profession are returning to a civic understanding of professionalism as necessary to maintaining public trust and, with it, professional privileges.[65,66] Dr William Sullivan wrote of this return to a classic role for the professions in society: “Historically, the legitimacy, authority, and legal privileges of the most prestigious professions have depended heavily on their claims (and finally their demonstration) of civic performance, especially social leadership in the public interest.”[63(p11)]

Ethically, therefore, when time is limited, physicians should be empowered and willing to use short-term holds to prevent immediate spread of disease, because physicians’ professional duty sometimes should tilt toward protecting the public—although not incidentally, of course, most individuals will also benefit from enforced isolation and treatment. Some physicians and patients, raised on the medical ethics of the last 50 years, will chafe at the paternalism of this statement, but we find that professionalism requires meaningful attention to civic duties such as protecting the public health. Because the power to hold patients involuntarily can be abused,[67] constraints such as requiring 2 physicians to concur, ensuring the short-term nature of the hold (24 hours or less), and ensuring rapid judicial review, should be applied. Legally, in jurisdictions where it is not clear whether physicians’ authority to hold patients for dangerousness applies outside the psychiatric setting, clarification is required. Bioterror training should reinforce physicians’ ethical obligations regarding isolation of dangerously infectious patients, and there should be open debates on appropriate limits to this power, as well as to address practical considerations regarding quarantine, such as when public health authorities should enforce community quarantine and how to respectfully care for those under quarantine.

TREATMENT: THE DUTY TO TREAT

Recent discussions of treatment barriers during bioterror-related outbreaks tend to focus on potential shortages of antibiotics and vaccines. But stockpiles can be calculated with reasonable certainty and increased as needed. More challenging in these scenarios is that 1 treatment variable is critically important yet very difficult to estimate: how many health care professionals will fail to show up for work because they fear contracting the illness?[68]

It is almost certain that some will not willingly face the risk. At least 1 hospital in China had difficulty maintaining services because of absenteeism in the face of SARS.[69] Some hospitals in New York have announced they will not care for victims of bioterror attacks.[70] Physician performance during epidemics, from the black plague to the HIV epidemic, has been notoriously spotty.[71–73] And relatively few physicians have volunteered to receive smallpox vaccination, despite high-level government requests.[74,75]

There is legitimate reason for trepidation on the part of health professionals. More than one third of health care personnel treating patients after the sarin gas attack in Tokyo became ill from cross-contamination.[76] Health care workers are common second-wave victims of Ebola[77] and SARS.[78] In the United States, there are 56 documented cases of health care workers’ becoming infected with HIV due to needlestick injuries,[79] and countless more have contracted hepatitis B or C, tuberculosis, and other potentially deadly infections. Into the 1950s, exposure to and infection with tuberculosis was a near-ubiquitous medical training experience, especially for pulmonologists.[80,81]

Several ethical and practical bases for a “duty to treat” have been proposed that taken together provide a strong justification for its reaffirmation today.[82,83] Health care professionals receive special training, which increases the general obligation to render aid to others in need, because it increases the value of the aid and may reduce the risk associated with providing it.[84] Physicians have long subscribed to explicit codes of ethics that demand the duty to treat,[85,86] codes that the public assumes to be binding. In 1991, despite recent interprofessional wrangling over the treatment of patients with HIV,[70] 72% of the public agreed with the statement that physicians are obligated to “treat all sick people.”[87] Physicians also receive social standing and trust as part of a social contract, which includes an obligation to place the welfare of patients above self-interest.[57]

When professional associations last confronted this issue, in the early years of the AIDS epidemic, early wavering gave way to consensus that a duty to treat still exists.[88] According to the Infectious Diseases Society of America and the American College of Physicians, health care professionals “must provide high-quality nonjudgmental care to their patients, even at the risk of contracting a patient’s disease.”[89(p576)] The American Medical Association’s recently (December 2001) adopted Declaration of Professional Responsibility states that physicians must “treat the sick and injured with

competence and compassion and without prejudice,” and “apply our knowledge and skills when needed, though doing so may put us at risk.”[90]

Two steps should be taken to reinforce this obligation. First, language in professional codes of ethics addressing treatment during epidemics was largely removed in the 1970s, at a time when epidemics appeared to be on the wane.[91] Subsequent statements focused almost exclusively on HIV/AIDS and often were framed in terms of antidiscrimination principles rather than professional obligations.[92] Professional associations should make clear their current stances on physicians’ obligations to care for patients during epidemics. Ideally, the inspiring spirit and language of the early American Medical Association Code of Medical Ethics should be reaffirmed today: “When an epidemic prevails, a physician must continue his labors for the alleviation of suffering people, without regard to the risk to his own health or to financial return.”[93(p354)]

Second, to justify and strengthen this obligation, special efforts should be made to ensure that health care professionals receive all reasonable preventive and treatment measures in the event of an outbreak, such as vaccines, prophylactic therapies, and safety training.[94] Such preferential treatment makes practical sense, because only healthy practitioners will be of value in responding to any ongoing threat.[95] Ethically, when health care professionals tend to patients in epidemics, healthy people place themselves (and often their families) at risk to benefit the common good. The state must recognize that this burden, in some manner, should be shared by the community as a whole. This value was implicitly recognized in policy discussions regarding early smallpox vaccination for health care workers. However, beyond smallpox, health care workers should be assured that in the event of an attack, all that is possible will be done to protect them—and their families. Local stockpiles of vaccines and other therapies should be set aside for health care workers, ensuring that those who may be at greatest risk will receive early and effective protection. In addition, the families of health care workers who perish in epidemics should receive predictable compensation. By offering fair compensation, the government can further spread the burden of pursuing the public interest.

CONCLUSIONS

Defense against bioterror and naturally occurring infectious epidemics requires a strong public health system. But the public health system cannot function without an effective health care system to detect, contain, and treat infectious diseases. Hence our national defense against bioterrorism must ensure universal rapid access to knowledgeable and compassionate health care professionals who in turn can and will evaluate and care for potentially contagious patients. When ethical barriers in the health care system stand in the way of detection, containment, and treatment, they must be confronted and resolved, because undiagnosed, unconfined, and untreated infections pose a risk to individuals and the community. ■

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Contributors

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Asthma Inhalers in Schools: Rights of Students with Asthma to a Free Appropriate Education

Sherry Everett Jones, PhD, JD, MPH, and Lani Wheeler, MD

Students who possess and self-administer their asthma medications can prevent or reduce the severity of asthma episodes. In many states, laws or policies allow students to possess and self-administer asthma medications at school.

In the absence of a state or local law or policy allowing public school students to possess inhalers and self-medicate to treat asthma, 3 federal statutes may require public schools to permit the carrying of such medications by students: the Individuals With Disabilities Education Act, Section 504 of the Rehabilitation Act of 1973, and Title II of the Americans with Disabilities Act. Local policies and procedures can be based on these federal laws to ensure that students with asthma can take their medicines as needed.

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MORE THAN 6 MILLION AMERICAN children aged younger than 18 years have asthma, making it one of the most common chronic diseases among children.[1] In 2001, more than 4 million children younger than 18 years had an asthma episode in the previous year (a rate of 57/1000), suggesting that many young people with asthma may not have their asthma under control.[1] As many as an estimated 1.4% of all American children experience some level of limitation owing to asthma, such as an inability (or limited ability) to engage in school or play activities.[2] Young people with asthma miss an estimated

14 million days of school each year because of the disease,[3] and some children's school performance consequently suffers.[4]

Provided parents or guardians and a health care provider, preferably with input from the child's school and especially the school nurse, deem it appropriate for a student to self-medicate and have granted authorization, it is beneficial to students with asthma to have unobstructed access to their medication before, during, and after school.[5,6] Students who self-administer their asthma medications can prevent or reduce the severity of asthma episodes.[7] However, some schools perhaps as part of a drug use prevention program or in hopes of minimizing liability claims, do not allow students to carry their inhalers in school.[8,9] In 2000, students were allowed to self-medicate with prescription inhalers in 68% of all schools nationwide (79% of middle/junior and senior high schools).[10]

Restrictions on students carrying their inhalers may preclude the immediate use of medication at the onset of symptoms. For example, the room in which the medication is kept may be too far from the student's classroom or playing field, some students may believe it is too disruptive to go to another part of the school building to take their medication,[11] and many students are embarrassed about needing to take medications.[12] Restrictions on the use of inhalers may ultimately compromise medication adherence, increase the risk of a full-blown asthma episode, and cause unnecessary suffering, emergency treatment, and asthma-related school absences.[2,8,13]

In 2000, approximately 223 children aged 0 through 17 years died as a result of asthma (a rate of 0.3/100 000).[1] Furthermore, asthma results in substantial increased use of the health care system. In 2000, children aged 0 through 17 years had an estimated 4.6 million asthma-related outpatient visits to doctors' offices and hospital outpatient departments (a rate of 649/10 000), approximately 728 000 asthma-related emergency department visits (a rate of 104/10 000), and approximately 21 000 asthma-related hospitalizations (a rate of 30/10 000).[1] Asthma-related missed school days among children aged 5 through 17 years resulted in an estimated cost of $726.1 million in caretakers' time lost from work.[14]

By knowing the rights of students with asthma, school administrators, educators, physicians, and other health care providers can help ensure that students have appropriate access to medications. This article explores state laws and policies that allow students to carry and self-administer asthma inhalers in school and federal statutes that may, under certain circumstances, require schools to allow students to do so.

STATE LAWS AND POLICIES ALLOWING INHALERS

As of April 2004, 38 states allow self-medication among students at school. Twenty-three states (Alabama,[15] Delaware,[16] Florida,[17] Georgia,[18] Illinois,[19] Kentucky,[20] Maine,[21] Massachusetts,[22] Michigan,[23] Minnesota,[24] Mississippi,[25] Missouri,[26] New Hampshire,[27] New Jersey,[28] New York,[29] Ohio,[30] Oklahoma,[31] Rhode Island,[32] Tennessee,[33] Texas,[34] Utah,[35] Virginia,[36] and Wisconsin[37]) have enacted legislation specifically to allow students with asthma to possess and self-administer inhaled asthma medications while at school. These laws require parental consent and permission from a physician or other health care provider. Also, the School Health Policies and Programs Study 2000 found that an additional 10 states (Kansas, Louisiana, Maryland, Nebraska, New Mexico, North Dakota, South Carolina, South Dakota, Vermont, and Washington) have adopted policies allowing students to self-medicate at school with prescription inhalers.[38] Five other states (California,[39] Connecticut,[40] Indiana,[41] Iowa,[42] and Oregon[43]) have laws broadly providing for the self-administration of medications. Because state laws are often changing, interested readers can access the National Conference of State Legislatures Web site to monitor legislative action related to asthma, including self-medication laws (http://www.ncsl.org/programs/esnr/asthmamain.htm).

ASTHMA AS A DISABILITY: FEDERAL STATUTES

In the absence of a state or local law or policy allowing students to possess inhalers and self-medicate, health care providers and parents might be able to use 1 of 3 federal statutes that, under certain circumstances, will provide the legal justification requiring schools to allow students with asthma to do so. Those laws are the Individuals With Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973 (Section 504), and Title II of the Americans With Disabilities Act (Title II of ADA).

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The purpose of IDEA is to partially fund states to develop special education programs "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living."[44]

IDEA applies only to children who meet the definition of a *child with a disability,* that is, a child with "mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (hereinafter referred to as emotional disturbance), orthopedic impairments, autism, traumatic brain injury, *other health impairments,* or specific learning disabilities; and who, by reason thereof, needs special education and related services" (italic added).[45]

The implementing regulations further define *other health impairment* as "having limited strength, vitality or alertness, in-

cluding a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that–(i) *Is due to chronic or acute health problems such as asthma* . . . ; and (ii) Adversely affects a child's educational performance (italic added)."[46]

To be classified as disabled under IDEA, a child with asthma must fall under the *other health impairment* category and require special education because of the asthma or have some other disabling condition under IDEA and require special education because of that disability. In either case, modifications must be made for that student that are determined necessary by the child's individual education program team and allow the student to receive a "free appropriate public education" (defined as education and related services provided at the public's expense, which meet the standards of the state educational agency, include an appropriate preschool, elementary, or secondary school education in the state involved, and are consistent with the student's individual education plan[47]), including "related services" designed to meet the child's unique needs.[44,48-50] Such related services might include allowing a student to carry an asthma inhaler.

SECTION 504 OF THE REHABILITATION ACT OF 1973

The purpose of Section 504 is to eliminate discrimination on the basis of a disability: "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . ."[51] Under this law, *disability* is more broadly defined than under IDEA and, consequently, covers a large number of youths with disabilities who attend federally funded programs not covered under IDEA. The federal regulations promulgated under Section 504 define a disabled person as one who "(i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."[52] The term *physical impairment* encompasses respiratory disorders or conditions. *Major life activities* refers to functions such as caring for oneself, breathing, and learning.[52] Section 504 is broader than IDEA because it applies to not only the education program, but also to other nonacademic and extracurricular activities.[53,54]

As with IDEA, the regulations promulgated under Section 504 require school districts to provide a "free appropriate public education" to children with disabilities.[55] In the context of Section 504, this requirement means that "the provision of regular or special education and related aids and services . . . designed to meet individual educational needs of handicapped persons [must be as adequate as those designed to meet] the needs of nonhandicapped persons. . . ."[56] Of note, some case law is in conflict with the Section 504 regulations requiring a free appropriate education. Some courts, including the US Supreme Court, have held that Section 504 does not impose an obligation for a free appropriate public education despite federal regulations to the contrary.[57] What this conflict means for future lawsuits is unclear. In accordance with the language of Section 504, courts consistently hold, however, that Section 504 requires that schools make reasonable accommodations to allow disabled students to gain equal access to educational opportunities provided at that school.[57]

TITLE II OF THE AMERICANS WITH DISABILITIES ACT

ADA extends Section 504 to public accommodations in the private sector and state and local public agencies that do not receive federal funding (the discussion of which is beyond the scope of this article).[58] In the context of disabled students attending public schools, Section 504 and Title II of ADA are similar. Title II of ADA prohibits any public entity (e.g., public schools) from discriminating on the basis of a disability.[59,60] Congress intended Title II of ADA and its implementing regulations to be consistent with Section 504,[54,61–63] although the federal regulations and the US Department of Education, Office for Civil Rights have interpreted Section 504 more broadly than Title II of ADA.[57] Under both Section 504 and Title II of ADA, recipients of federal funds and public entities must address the disability-related needs of disabled students so they can participate in services or programs to the extent necessary to avoid discrimination.[54] The definition of *disability* under Title II of ADA is identical to that of Section 504. Under the regulations of Title II of ADA, a school must "make reasonable modifications in policies."[54] A school that refuses to administer medication because of a student's disability would be in violation of Title II of ADA.[48]

HOW THESE FEDERAL STATUTES HAVE BEEN APPLIED

A clear demarcation indicating at what point a child's asthma rises to the level of a disabling condition is not available. Presumably, when a child's asthma significantly interferes with breathing, the child would be considered to have a disability.[58] Parents and the child's health care provider, along with teachers, the school nurse, and other school officials, are in the best position to evaluate the effect a child's asthma has on a child's health and academic performance. Gelfman and Schwab recommend that health professionals document the following: "(1) how the disability interferes with 1 or more life functions [e.g., breathing, learning]; (2) how the disability affects the student's functioning (e.g., energy level, exercise needs, medication effects, etc); and (3) what individualized supports or accommodations in school the student requires in order to access an appropriate education."[58(p337)]

When a child's asthma is disabling to the extent that the child needs "special education and related services,"[45,46] under IDEA a school is obligated to offer that student sufficient specialized services (e.g., allowing a student to carry an asthma inhaler) so that the student may benefit from his or her education.[50,64] During 2000–2001, the US Department of Education estimated that 292 000 children aged 3 to 21 years were served under IDEA as a result of a disability categorized as "other health impairment."[65] The US Supreme Court, in *Cedar Rapids Community School District v Garret F,* established that under IDEA, those services may go as far as providing a full-time, one-on-one nurse or health assistant.[66] If a student has no other disability and the student's asthma does not affect his or her educational performance, IDEA does not apply.[67] However, students who need access to an asthma inhaler because their asthma places a substantial limitation on major life activities (i.e., the child is disabled because of his or her medical condition) but do not need special education remain qualified under Section 504 and Title II of ADA[68,69] and may avoid being labeled as children who need special education.

To succeed in a Section 504 or Title II of ADA claim alleging that an accommodation was not granted, the claimant must show that the accommodation was denied because of the student's disability (i.e., was discriminatory).[54,70,71] In *East Helena (MT) Elementary School District # 9,* the school district refused to either administer or ensure that the student took asthma medication prescribed and filled by a naturopathic physician.[70] Instead, the school offered to allow a family member to administer the child's medication. In refusing to administer the medication, the school district was following a state law that prohibited the administration of medication unless the prescription was filled by a pharmacist. In that case, the court upheld the policy because the refusal applied to all students regardless of disability status.

Similarly, in *DeBord v Board of Education of the Ferguson-Florissant School District*[54] and *Davis v Francis Howell School District,*[71] schools refused to administer a prescription medication (methylphenidate [Ritalin] for attention deficit hyperactivity disorder) because the doses exceeded that recommended by the *Physicians' Desk Reference.* Both school districts had policies prohibiting schools from administering such prescriptions, although both were willing to let a parent or designee come to the school to administer the medication. The schools argued that the policies were to protect students' health and minimize potential liability. Courts in both cases found that because the school policies were neutral and applied to all students regardless of disability status, no discrimination had taken place. *DeBord, Davis, and East Helena* are examples of situations in which the claimant could not show that the school district's refusal to accommodate the child was based solely on a disability; therefore, no violations of Section 504 or Title II of ADA were found.[54,70,71]

Although some school policies that forbid staff to administer medications to students have been upheld by courts if uniformly applied, it is unlikely that a "no medications" policy (i.e., a policy that denies the administration of any and all medications at school) applied to all students would stand up in court because those policies have the effect of denying children with disabilities the free appropriate public education to which they are entitled under IDEA and perhaps Section 504, or reasonable accommodations under Section 504 and Title II of ADA.[57,72,73] A free appropriate public education must be specifically designed to meet the unique needs of the child,[74] and consequently, related services, including medications, must accompany that design.[55,56,66] Likewise, under Section 504, health services provided as part of related services must be individually evaluated and prescribed.[58]

INDIVIDUAL EDUCATION PROGRAMS

Under IDEA, a "child with a disability" must be provided with an appropriate individualized educational program (IEP).[49,75] Federal regulations promulgated under Section 504 indicate that schools may use IEPs or other plans as a means of meeting free appropriate public education requirements included in those regulations[55] (whether Section 504 includes such requirements is less clear[57]). An IEP is a written statement designed to identify a child's educational needs and other programs and related services the child requires to progress in the general curriculum.[49] IEPs are developed by an IEP team that typically includes the disabled child's parents, regular and special education teachers, and other representatives from the local education agency who are best suited to assist the child in meeting his or her educational needs.[49] A school nurse may be part of the IEP team when school health services (e.g., administration of medications) are necessary.[76] This team, created specifically for each individual child, ensures that all aspects of the child's educational and related services needs are tailored to that child. This team, along with consultation from the child's health care provider, is best equipped to determine on a case-by-case basis whether self-medication using asthma inhalers is appropriate.

For students with asthma, an *asthma management plan* (Table 1) is an appropriate part of an IEP.[5] Health care providers give instructions on how best to manage the child's asthma during the school day. For a student with asthma, it is helpful if part of the IEP (or 504 plan or individual health service plan or asthma management plan) includes specific information about where, when, and how each asthma medication is to be taken, including when medication possession

TABLE 1—Elements of Typical Asthma Management Plan

- Student's asthma history
- Student's asthma symptoms
- How to contact student's health care provider and parent or guardian
- Signatures of physician and parent or guardian permitting use of medications in school
- List of factors that make student's asthma worse
- Student's best peak flow reading (if student uses peak flow monitoring)
- List of student's asthma medications
- Student's treatment plan, including actions school personnel can take to help handle asthma episodes

Source. NIH Publication 95-3651.[5]

and self-administration provisions are appropriate.

It is best if asthma management plans are on file in the school office or health services office and available to teachers and coaches. From a legal perspective, it is recommended that the asthma management plan include parental permission for the plan to be shared with relevant school personnel to avoid possible violations of the Family Education Rights and Privacy Act of 1974 (FERPA), which prohibits the unauthorized disclosure of confidential information in education records (including school health records in most cases).[77,78] However, under FERPA education records may be released to school officials without written consent of students' parents, including to teachers within the educational institution or local education agency, who have a "legitimate educational interest."[79] Under FERPA, it is important to note a narrow emergency exception whereby a school may disclose personally identifiable information to appropriate parties in connection with an emergency if knowledge of the information is necessary to protect the health or safety of the student.[77,80]

OVERCOMING POTENTIAL DISADVANTAGES

Although many advantages to self-medication exist, families and schools need to recognize some theoretically possible disadvantages of students' being responsible for carrying and administering their own medication. These disadvantages can be minimized, however. First, students may unintentionally leave their inhalers at home or misplace their inhalers at school. One possible solution is to keep a spare inhaler in a school nurse's office or health room.

Second, self-medication may make it more difficult for the school to keep medication records. Such documentation ensures that medication adherence can be communicated to parents and children's health care providers; documentation might be required as part of an IEP or Section 504 plan or might be recommended by school boards as a way to monitor the health and safety of students. To solve this problem, schools could require that students report each inhaler use to a school nurse or record each medication use in a diary.

Third, students may not be well educated about when to take their medications,[8,81] may be embarrassed to take their medications in front of peers,[8] or may lack the maturity to use their medications appropriately (e.g., most elementary school students). Health care providers and parents are primarily responsible for teaching children about administering asthma medications and determining on a case-by-case basis whether the student has reached a level of maturity necessary for self-medication. School-based programs can supplement student education by helping students with asthma understand their disease and the importance of asthma self-management[82,85] as well as destigmatize the need for using asthma inhalers during the school day.[83]

CONCLUSION

Not all students with asthma have their asthma under good control.[1,4] Patient education and medical management about the proper use of asthma medication are crucial to preventing asthma morbidity and mortality.[86,87] For optimal asthma management, it is important that students with asthma not be denied appropriate access to their medications in school.[5,6,11,88,89] Many states have laws or policies that allow students to self-medicate with asthma inhalers at school (there is no evidence on whether state laws or polices are more effective to ensure immediate access for students in schools). In addition, 3 federal laws require schools to accommodate students whose asthma qualifies as a disability under IDEA, Section 504, or Title II of ADA. Such accommodations may include allowing students to carry their asthma inhalers so they can self-medicate as indicated in their asthma management plan. Of note, the US Department of Education, Office of Safe and Drug-Free Schools has issued guidance clarifying that "a student's prescription drugs, and related equipment, are not illegal drugs and are not prohibited by the [Safe and Drug-Free Schools and Communities Act]."[90]

Although these laws and policies are important, they cannot provide an individualized answer to asthma management. Ideally, parents or guardians, the child's health care provider, and school personnel, including the school nurse, will work together as a team to determine the best way to manage a student's asthma in school. Table 2 outlines some factors that should be considered in determining the appropriateness of self-carrying and self-administering inhalers in school. For example, whether a child with asthma should be permitted to self-medicate ought to be determined on a case-by-case basis, based on a child's abilities and interest and maturity and the situation at the school. When that team deems the child skilled and mature enough, the student with

TABLE 2—Elements to Consider When Determining Appropriateness of Self-Carrying and Self-Administering of Inhaler Medication in Schools

Student factors
- Asthma severity and morbidity (hospitalizations, emergency department visits, severe episodes, types of triggers)
- Student's asthma knowledge, attitude, skills, and behavior (awareness of asthma signs and symptoms, desire to self-carry inhaler, willingness to self-administer and report use of inhaler, understanding of importance of not sharing inhaler with other students, correct peak flow and inhaler technique)
- History of asthma episodes at school
- Adherence to school rules regarding medication administration
- Inhaler self-carrying experience in other settings (child care, camp, after-school care, at friends' homes)

Family factors
- Desire of parents/guardians for student to self-carry and self-administer medications with an inhaler
- Collaboration of parents/guardians with school team; permission for physician and school to share information

School factors
- Health staff availability (whether or not there are full-time school nurses or health assistants)
- School size (whether or not there is quick and easy access to health room)
- Ability to reduce student's triggers at school
- Proximity and availability of inhalers from local emergency medical services

Health care provider factors
- Completion of physician's or other health care provider's written asthma management plan and all required forms
- Student's education by physician or other health care provider about asthma generally, controlling asthma, and proper use of inhalers, spacers, and peak flow meters
- Assessment by physician or other health care provider of student's technique for inhaler, spacer, and peak flow meter use

asthma should be allowed to keep asthma inhalers in his or her possession[11,88] to reduce the chances of a full-blown asthma episode, asthma-related school absences, and the need for emergency medical care.[8,86,87] Some students may not want or need to carry their inhalers, for example, when the school building is very small and health staff are available during all school hours. Each student needs individual assessment as part of the implementation of that student's personal asthma management plan.

In some circumstances, parents may need assistance from the child's physician or other health care provider in advocating for the student to gain the right to self-carry an asthma inhaler. By knowing the rights of students with asthma, physicians and other health care providers can help ensure that students have appropriate access to medications at school. An informed health care provider can bring to the attention of school administrators and educators, as well as parents, the legal requirements of schools with students with asthma, and the benefits of self-administration and adequate control of asthma (e.g., improved health and fewer school absences). For example, health care providers can obtain parental permission to send a written asthma management plan to schools including specific guidance about the student's skill and maturity regarding self-administering the asthma inhaler. They can personally contact the principal if there is reluctance to permit self-carrying of inhalers. Students are more likely to be able to control their asthma when school personnel, parents or guardians, and health care providers know about disability laws and about appropriate asthma management. ■

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S. Everett Jones collected, analyzed, and synthesized the literature and wrote the article. L. Wheeler assisted in synthesizing the literature and contributed to the writing the article.

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