Understanding a brief history of cleft care advocacy will help guide future advocacy goals.

Individuals with clefts require advocacy at the government level, in schools, and where they are treated for their condition.

Key legislation has benefited children with cleft conditions and their families.

Resources are available for affected individuals to treat the whole person and provide comprehensive care across the lifespan.

Practitioners should be familiar with the ACPA Parameters of Care and the ACPA Team Standards.

The dictionary defines *advocate* as “one who supports or promotes the interests of another” and defines *lobbyist* as “one who influences or sways someone toward a desired action.” The manner in which a person supports and promotes the interest of another often determines whether the person is lobbying or advocating for a specific cause or condition. The ability to lobby is often determined by the articles of incorporation of the institution or organization that is being represented. The articles of incorporation of most nonprofit organizations are written in such a way that lobbying is not permitted, but advocacy in the form of public education is often within the scope of the bylaws. An excellent example of this is found in the bylaws of the American Cleft Palate-Craniofacial Association, wherein it is clearly stated that “the association shall not participate or intervene in any political campaign on behalf of any candidate for public office.” Therefore, using the powers of the association to influence the election of a specific candidate would violate the bylaws of the organization, as would donating money in the name of the association to the campaigns of specific legislators who might support a specific health care bill. The Cleft Palate Foundation has a similar clause related to lobbying, but clearly states in the preamble to their bylaws that it is acceptable to facilitate and encourage the care of affected individuals. Therefore testifying to the legislature for continued support for the funding of cleft and craniofacial programs, with the assertion that the provi-
sion of such care would enable affected individuals to enjoy a higher quality of life, for example, would be an acceptable form of advocacy and would not be considered lobbying.3

Advocacy related to the care of individuals affected by clefts and craniofacial conditions can be multifaceted, because it may relate directly to patient care, as exemplified by the education of a school system on the need to continue speech services throughout the high school years, or it can be in the form of third party–payer education concerning the medical necessity of a surgical procedure that might otherwise be deemed cosmetic in nature. In addition to the external advocacy often required for direct patient care, institution-based cleft and craniofacial teams are often placed in the position of defending their existence because of reimbursement challenges related to team evaluations. The education provided at the institutional level by the directors of cleft and craniofacial programs in defense of the benefits of interdisciplinary team care is a form of institutional advocacy.

Advocacy in the health care environment has become integral to the care of patients with special health care needs, because without the education provided by the consumers of services and the organizations that represent those who provide care, the successful passage of specific health care legislation and regulations would be unlikely. Legislation relative to insuring patients for preexisting conditions, for example, exemplifies the role that advocacy has played in the passage of laws that may benefit individuals with a cleft. The public and professional education provided by both consumers and providers of cleft and craniofacial care have helped to shape the provision of care in the United States since the 1930s; for example, the passage of the Federal Maternal Child and Health Act and the extension of Social Security for individuals with handicapping conditions have enabled most children in the United States to have access to basic cleft care, regardless of their family’s ability to pay.

HISTORY OF MATERNAL-CHILD HEALTH SERVICES IN THE UNITED STATES

The crash of the stock market in 1929 resulted in a major decline in income and the ability of many families to provide basic nutrition and medical care for their children, especially those affected by infantile paralysis and other crippling conditions. Legislation passed in the 1930s to assist dependent women and children, enable families to obtain basic nutrition such as milk and cheese, establish prenatal clinics, and ease the burden on families caring for children with polio. Known in many states at the time as the Crippled Children’s Act, it formed the basis of today’s Federal Title V Maternal and Child Health Program, one of the subsidies available today for children with special health care needs. The Maternal and Child Health Program was modified in the 1980s into a block grant that has become a match of both federal and state monies.4 However, the allocation method for this money for the care of children with clefts and other craniofacial conditions is determined by the departments of health in each of the states. Title V money is known as last-dollar funding and can only be accessed after all other third-party funding resources, including Medicaid, are exhausted. The allocation of these monies in the form of direct patient care is entirely state dependent, especially with respect to the care of those with clefts and other craniofacial conditions. Although the federal government sets the parameters that make this money last-dollar spending and targets specific initiatives that must be addressed in the states’ funding plans for this money, the allocation of the funding to address these initiatives is state dependent. Access to Title V money by an individual state requires the state to submit a comprehensive spending plan to the federal government every 5 years, with annual updates addressing the federal initiatives. Because the state must reapply every 5 years, vigilance on the part of the consumer and the providers of health care is needed.

Most states review the health priorities addressed by the Maternal and Child Health Block Grant at an annual public hearing. At the time of these reviews, public comment is sought regarding the initiatives addressed and those initiatives that might be lacking. Consumers and providers of the services outlined in these plans are encouraged to give both oral and written testimony. Interestingly, a lack of advocacy
certain states has resulted in language specific to clefts and craniofacial conditions being removed from the health plan and replaced with more generic language such as “children with special health care needs.” The removal of specific language can potentially place one childhood health problem in competition with another for funding.

The state of Pennsylvania was once a model for the provision and funding of services related to cleft care because of the dedication and persistence of Dr. Robert Ivy and Dr. Herbert Cooper in the 1950s. Drs. Ivy and Cooper spent a good deal of time educating Pennsylvania legislators about the comprehensive care needed for children with clefts and craniofacial conditions and the need to understand that without appropriate interdisciplinary care, an orofacial cleft could be a handicapping condition. The education provided to the legislature by these individuals resulted in coverage for care and a dedicated oversight program for that care under maternal and child health services. The cleft program in Pennsylvania continued for decades, and its viability was taken for granted; however, lack of vigilance by providers and recipients of this care in the late 1990s and early 2000s resulted in the loss of specific language and funding related to cleft and craniofacial care.6

Both providers and consumers of services for children with special health care needs can take an active role educating legislators and public health officials on the needs of individuals with clefts and craniofacial conditions by submitting testimony when maternal child health plans are reviewed at the state level. The public hearing dates for these plans can be found on the Department of Health website for each state. Plans are generally reviewed in the spring of the year, and public comment is welcome.

SUPPLEMENTAL SOCIAL SECURITY INCOME

Individuals with certain types of disability may be eligible for supplemental income through Social Security and state Medicaid. The ability of those affected by clefts or craniofacial conditions to receive any of these funds depends on an application process rating the disability and family income. Families with members who have a craniofacial condition, especially those with conditions requiring a great deal of medical and custodial intervention, should apply for the supplemental income. Applications can be made through a local Social Security office.6

INSURANCE LEGISLATION AND HEALTH CARE

Despite federal legislation concerning health insurance and the requirements for basic coverage, many commercial group insurance plans are generally regulated by the state rather than by the federal government. The regulation of commercial group insurance plans is entirely state dependent; therefore it is impossible to generalize what is and is not covered relative to cleft and craniofacial care. Many states, for example, have legislation relating to the need to cover all aspects of cleft and craniofacial care, including dental care and, in some instances, hearing aids and augmentative communication appliances. In most instances, however, regulations only apply to group insurance plans written by commercial insurers. The insurance commissioner in each state usually has jurisdiction over such plans and can mandate, after review of an insurance denial, that the commercial insurer cover a procedure.

Unfortunately, however, many insurance providers and other third-party payers fall outside of the jurisdiction of the insurance commissioner and state-specific legislation because the insurance plan is either a self-insured plan or a managed care plan. Many businesses self-insure their employees, and many trade unions underwrite insurance through their health and welfare plans. Self-insurance plans are not regulated by state legislation but are federally regulated. Businesses that self-insure their employees must provide plans that have minimum benefits under the Employee Retirement Income Security Act of 1974 and the Affordable Health Care Act. Union health and welfare insurance plans are governed by the Department of
Labor, and the review of an insurance denial relative to these plans has multiple layers. When appeals are required for either a self-insurance plan or a union-based plan, the starting point after the required appeal process by the insurer is the human resource or personnel department at the employee’s place of employment. The regulation and appeal process within a given state is quite variable. For example, regulation in New Jersey is provided by the Department of Health, and regulation in other states may be under the division of Banking and Insurance. The best informational resource for all insurance issues is the office of the state’s insurance commissioner. This department should be able to direct individuals to appropriate regulatory resources for information on appeals.

**SPECIAL HEALTH NEEDS AND PUBLIC EDUCATION**

Although individuals with clefts or craniofacial conditions may never require a specialized educational environment, many require special education or school-based therapeutic services. The 1970s federal law governing the education for all children with handicapping conditions widened the scope of services provided by a school district. Known as Public Law 94-142 initially and later renamed the Individuals With Disabilities Education Act (IDEA), it mandated that all states make available to children with disabilities a free and appropriate education in the least restrictive environment. This law established procedures by which children with disabilities should be evaluated and classified to provide them with appropriate individualized educational plans (IEPs). The law ensured that the IEP would be jointly developed by the parents and school officials.

Because all states are federally mandated to provide specialized education, the process of obtaining special education is similar in all states in respect to due process of the law. In addition to education starting at the first grade level, most states have early intervention programs for children from birth to 3 years of age who have developmental delays. Obtaining information about programs for children younger than 3 years is best done by contacting a state’s Division of Mental Health and Mental Retardation. Parents of children between the ages of 3 and 6 years who need special educational services can usually obtain information through the local school district. The school district can then refer families to the appropriate resource for continued educational testing and support.

Additional programs within local school districts—known as 504 plans—are available for the monitoring of a child’s special needs when an IEP is not needed but occasional monitoring of progress is. An example of a 504 plan is the monitoring of a developmental speech issue that currently may not need therapy but may require therapy at a later date. Another example of a 504 plan would be that of special accommodations for a child with attention deficit hyperactive disorder in a testing situation when a special education program is generally not necessary. Again, the need for special education or accommodation is best discussed with the local school district, and the district should direct families to appropriate resources for this accommodation, such as a child study team or a school counselor. In general, therapeutic services such as speech, occupational, and physical therapy are available to children with special health care needs when that need affects their educational ability.

The professionals and families caring for individuals with clefts and craniofacial conditions need to work together to advocate for special education and therapy in the school system. A team approach is the best approach for the habilitation process for affected individuals, but not all services can be always be provided conveniently in the cleft team setting. Extending the cleft team into the educational realm is often needed to provide individuals with services in the least restrictive and most geographically appropriate environment. Professionals treating children with special health care needs must therefore be willing to both educate and advocate for the therapies needed when school-related issues arise. Advocacy resources may be available to families when educational road blocks are encountered through the offices of their local state legislators, education law centers, and university law schools.
INTERNAL ADVOCACY FOR THE CLEFT TEAM AND ADVOCACY FOR PROFESSIONAL EDUCATION

The interdisciplinary team approach that is advocated for the care of individuals with clefts and craniofacial conditions is often a limiting factor to adequate reimbursement for evaluation services at the institutional level, primarily because of the unique nature of the American Medical Association CPT coding system that is universally used to obtain payment for medical procedures and evaluations in the United States. Because a comprehensive code for team care is not available, reimbursement to teams for their extensive evaluations is often compromised, limiting fee-for-service income to teams. The reduction of income to teams because of the inability to obtain reimbursement for comprehensive evaluations done at the same facility and on the same day can place the directors of centers in a position of needing to defend the continued existence of their centers in hospitals and universities.

Although both the Parameters of Care for Cleft and Craniofacial Conditions and the Team Standards for Cleft-Craniofacial Teams endorse interdisciplinary evaluation and treatment, financial justification for continuation of cleft and craniofacial centers can be difficult. Thus the directors of these centers, who often find themselves in the position of advocating for their continuation, must have documentation of the downstream revenue to other services within their institution and the impact that having or not having a center would have on the community. A recent publication has indicated that, when carefully analyzed, cleft and craniofacial centers in hospitals at the very least break even, and in most cases provide profit, to the institution through downstream revenue from the operating room, laboratory, and radiology.9

Ironically, acceptance of interdisciplinary team care as the standard of care has created some important gaps in professional education, because patients are most often treated in major centers rather than in community-based facilities. Thus community-based practitioners have limited exposure to this type of patient. Because there are limited opportunities for community-based practitioners to treat cleft and craniofacial patients, many graduate programs have limited the exposure of their students to the field. The responsibility of teaching young professionals about the interdisciplinary care and discipline-specific care needed by individuals with clefts and craniofacial conditions has become in large part the responsibility of the practitioners on treatment teams. The American Cleft Palate-Craniofacial Association, for example, has now developed alliances with other professional organizations, the goal of which is to help ensure that community practitioners have the knowledge to treat individuals with craniofacial conditions through continuing education experience. Advocacy by craniofacial practitioners, researchers, and professional organizations regarding the need for graduate and postgraduate education that addresses the care of individuals with these conditions will help to ensure the availability of future generations of practitioners.10

WHY ADVOCACY?

The ability to evaluate and treat individuals with special health care needs in an interdisciplinary fashion developed as the result of consumers and practitioners placing appropriate pressure on programs that support the care of these individuals.11 Third-party payers now rarely deny payment for the repair of a cleft lip because the payer considers the procedure to be cosmetic in nature. Every time care providers mentor a student or appeal an insurance claim, they are advocating for care. If care is to continue to advance, those working in the realm of cleft and craniofacial services, whether in the home, the laboratory, or the hospital, must remain vigilant and noncomplacent as they educate younger generations of practitioners, the general public, and their legislators.
CONCLUSION

Health care advocacy is multifaceted and the role of the providers of cleft and craniofacial care in this process is as diverse as the care itself. To ensure the availability of appropriate care, as recommended by the ACPA Parameters of Care\(^1\) and the ACPA Team Standards,\(^2\) providers and consumers of care must cooperatively advocate by educating the public, legislators, school systems, health care systems, third-party payers, and those writing the curriculum for related professional training programs on a continuous basis.

Ensuring that care and advances in diagnosis and treatment are available to individuals with clefts and craniofacial conditions involves major effort by those providing care and those engaging in related clinical research. Every time a provider of care challenges a negative decision on the part of a third-party payer regarding a recommended treatment, that provider is advocating for the needs of affected individuals. Knowledge of every avenue that can be taken to change a negative decision regarding a recommended treatment or therapy further ensures that state-of-the-art care will remain available. Consumers, providers, and researchers can and should testify on legislative issues related to health care to maintain and advance the availability of interdisciplinary care. Removing some of the roadblocks to care and research through the education of legislators, government officials, and institutional administrators is one of the best forms of advocacy.

Advocates of cleft and craniofacial care must have written data that includes who and what will be affected by their efforts, as well as published data that relates to a proposed program or project and to the consequences of not having such a program. Appeals of insurance coverage denials, for example, should include published data supporting the need for procedure, of the consequences to the patient if the procedure is not performed, and of the financial impact on the insurer if additional treatment is later required as a result of the denial for services. School issues should be addressed in a similar manner. It is important to remember that staff in the offices of both local and federal legislators can be helpful with many aspects of health care advocacy, including the appeal of denials for supplemental Social Security income or school-based therapy. The administrative staff in legislative offices is usually knowledgeable about the regulations and laws dealing with health care insurance; related pending legislation; and the avenues to successfully work with Social Security, school systems, and both Medicaid and subsidized health insurance.

REFERENCES