



Consent by Proxy for Nonurgent Pediatric Care

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Minor-aged patients are often brought to the pediatrician for nonurgent acute medical care, physical examinations, or health supervision visits by someone other than their legally authorized representative, which, in most situations, is a parent. These surrogates or proxies can be members of the child's extended family, such as a grandparent, adult sibling, or aunt/uncle; a noncustodial parent or stepparent in cases of divorce and remarriage; an adult who lives in the home but is not biologically or legally related to the child; or even a child care provider (eg, au pair, nanny, private-duty nurse/nurse's aide, group home supervisor). This report identifies common situations in which pediatricians may encounter "consent by proxy" for nonurgent medical care for minors, including physical examinations, and explains the potential for liability exposure associated with these circumstances. The report suggests practical steps that balance the need to minimize the physician's liability exposure with the patient's access to health care. Key issues to be considered when creating or updating office policies for obtaining and documenting consent by proxy are offered.

abstract

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BACKGROUND

Before providing nonurgent medical care to a minor patient not accompanied by a legally authorized representative (LAR), important questions regarding informed consent and the delegation of parental responsibilities need to be asked and answered. These questions include the following:

1. Who has a legal right to delegate consent to health care decisions for a child?
2. To whom can the power to consent to health care for a child be delegated?
3. In what circumstances can the power to consent to health care for a child be delegated?
4. What are the limitations on the right to delegate the power to consent to health care for a child?

5. How is authorization of proxy consent verified and documented?
6. When or how often does information on proxy consent need to be updated?

Many aspects of informed consent in pediatrics have been set forth in previous policy statements from the American Academy of Pediatrics (AAP). Some of these statements addressed informed consent in broad terms, and others addressed narrowly focused situations. The AAP statement on informed consent¹ noted that, unlike in other specialties, “the doctrine of ‘informed consent’ has limited direct application in pediatrics,” because parents or other surrogates provide informed permission, rather than informed consent, for diagnosis and treatment of children. Other AAP policy statements have provided guidance to pediatricians on consent for treatment of minor patients in specific circumstances such as emergency care,² genetic testing and newborn screening,³ procedures that involve sedation,⁴ and parental denial of medical care for religious reasons.⁵

This report does not replace the aforementioned policy statements; they stand on their own merit. In addition, it is important to recognize the relevance of the AAP policy “Achieving Quality Health Services for Adolescents”⁶ (noting the importance of confidentiality for quality adolescent care). This clinical report does not replace or supersede this policy, nor does it apply when a parent has given consent during an early- or mid-adolescent visit for a pediatrician to provide ongoing care to the teenager alone.

Instead, this report addresses the potential liability risks that physicians may incur when providing nonurgent medical care to pediatric patients without obtaining permission or consent directly from the patient’s LAR. This report is a revision of the

2010 clinical report on consent by proxy.⁷ The authors acknowledge that not permitting consent by proxy may pose a challenge to the efficient operation of a busy pediatric practice. However, suggestions are offered to help pediatricians minimize their exposure to legal risk in situations in which an LAR has delegated the authority to consent to nonurgent medical care to another adult. Pediatricians should use their good judgment in balancing the patient’s health care needs with their own need for legal protection. Because pediatricians are primarily concerned with their patients’ welfare, discretion should be used to differentiate situations in which care can be delayed pending appropriate LAR consent from situations in which the pediatrician should provide care and accept the risk of legal repercussions. Careful planning and good office policies can minimize those instances.

LEGAL BACKGROUND

All states, as supported by AAP policy, allow the provision of specified services (eg, the treatment of sexually transmitted diseases) to minors without parental consent. In general, however, people who have not yet reached the age of majority are not considered adults and do not usually have the right to consent to their own medical care. In most states, the age of majority is 18 years. Thus, a physician is required to obtain consent from an LAR before performing a medical or surgical test, procedure, or treatment on a minor.⁸ Under some scenarios, the consent can be obtained from the LAR via telephone, even if a proxy accompanies the minor. It is advisable to have a witness confirm and document phone consent. In addition, judicial decisions and legislative action have resulted in several exceptions to the LAR-consent requirement, which depends

on the specific state rule (eg, emergency treatment; treatment of an emancipated or “mature” minor; treatment of an adolescent for a specific clinical situation such as sexual assault, sexually transmitted infections, contraception, pregnancy-related care, mental health disorders, drug abuse, or alcohol dependency).

A physician who provides nonurgent care, including the physical examination, to a minor without the consent of someone who is legally authorized to speak for the minor may be vulnerable to legal action. Lawsuits that allege a lack of informed consent usually are based on the concept of negligence but may involve battery as well.^{9–11} In general, battery is the unsolicited physical touching of a person. Medical battery may be alleged if treatment is provided without appropriate informed consent, when a procedure is performed that is substantially different from the one for which consent was given, when the treatment exceeds the scope of the consent, or when a physician different than the one to whom consent was granted performs the procedure.¹² A physician may face a battery claim even if the treatment or procedure may have been performed without any negligence.¹³ When a plaintiff (person who files the lawsuit, usually parents on behalf of their child) is not satisfied with the results of the medical treatment or procedure but is unable to prove negligence in litigation against the physician, the plaintiff may resort to the theory of battery to seek a recovery. If the plaintiff who alleges an unauthorized procedure cannot prove actual harm, typically only nominal damages will be recovered. However, in a successful battery case, punitive damages may be assessed, which may not be covered by malpractice insurance or dischargeable by bankruptcy. Some states have replaced the

theory of battery with the theory of medical negligence. In addition to civil liability, physicians may face penalties from licensing boards for performing services without appropriate consent.¹⁴

The impact of state privacy laws and the federal Health Insurance Portability and Accountability Act (HIPAA)¹⁵ on physician liability for disclosure of health information of minors to unauthorized individuals has not yet been tested. Although HIPAA, as a federal law, takes priority when it conflicts with state laws, in most situations HIPAA expressly incorporates state laws regarding disclosure. To date, physician liability for treating without consent by an LAR seems to be uncommon. However, past frequency may not reflect future likelihood, because the concepts of informed consent and consent by proxy have evolved both ethically and legally. In fact, inadequate informed consent, which had not previously been a major source of liability for physicians, has become increasingly problematic, especially in the context of issues such as limited English proficiency (LEP) and limited health literacy (discussed later). Consent by proxy could become a source of future concern, and physicians should not ignore the risks associated with it.

Many of the published cases are of older judicial decisions.¹⁶ The ramifications of these cases are unclear to a contemporary jury and judge. In addition, these older cases did not address issues such as LEP and limited health literacy, which may affect informed-consent situations, including consent by proxy. In many of these cases, treatment without consent by an LAR was deemed appropriate by the court either on the basis of the emergency treatment doctrine or because the court deemed the minor patient to be a “mature” or emancipated minor.¹⁶

However, there is also judicial precedent in which liability was imposed on the physician.^{10,17–19}

Although not specifically addressing consent by proxy, more recent court cases have assessed the validity of informed consent when a parent was not present.^{20,21} These cases have involved consent by adolescents for treatments and diagnoses other than those already permitted in most jurisdictions, such as treatment of sexually transmitted infections and mental health disorders. In viewing the informed consent as valid, these courts have determined that the adolescents were “mature minors,” although the minors had not previously sought mature-minor status through adjudication. The courts relied on the adolescents’ age, ability, education, training, degree of maturity and judgment, conduct and demeanor, and the nature and risks of the treatments in assessing whether the minor adolescents were capable of consenting on their own. Nevertheless, despite this legal precedent, pediatricians should be wary of treating adolescents without parental consent unless the adolescent is seeking treatment of a legally permitted condition.

A claim of “inadequate” informed consent is usually predicated on the notion that a “reasonable” person would have refused the treatment or procedure offered to the plaintiff had proper informed consent been conducted.¹² A claim of inadequate informed consent may be added to a claim of medical malpractice because proof of inadequate informed consent might imply to a jury that the physician was careless about the care delivered.²² The importance of appropriate informed consent is underscored by appellate court decisions that held that neither proof of medical malpractice nor battery is required for a claim of inadequate informed consent to be valid.^{23,24}

DEFINITION OF TERMS

Nonurgent Pediatric Care

For the purposes of this clinical report, nonurgent pediatric care is defined as preventive medicine (ie, services encompassed in pediatric health supervision visits, including immunizations and screening tests) and outpatient medical encounters for minor illnesses or injuries. Differences in operations and procedures may depend on whether the nonurgent medical encounter is the initial visit or a follow-up visit.

Informed Consent

Informed consent is a general principle of law that imposes on physicians a duty to disclose to their patients the benefits and risks associated with each of the following: (1) the proposed course of treatment, (2) alternate treatments, and (3) no treatment at all (informed refusal). In general, informed consent is meant to allow patients to exercise their right to autonomy and to voluntarily consent to medical interventions by reasonably balancing the probable risks against the probable benefits.²⁵ State standards in assessing the adequacy of disclosure under informed consent can be physician/professional based (ie, benefits and risks that a reasonable physician would disclose), patient based (ie, benefits and risks that a reasonable patient would want to know), or a hybrid of both. Some states have appointed interdisciplinary panels to develop specific informed-consent disclosure requirements for selected procedures.²⁶

Consent by Proxy

The process by which people delegate to another person the legal right to consent to medical treatment of themselves, for a minor, or for a ward is called consent by proxy. There are 3 fundamental constraints on this right to delegate consent for children: (1) the guardian of a minor must have the right to consent to

medical treatment of that minor, (2) the guardian must be legally and medically competent to delegate the right to consent to medical treatment of that child, and (3) the right to consent to medical treatment of the child must be delegated to a legally and medically competent adult.^{8,16,27} Physicians should realize that people who have been delegated consent-by-proxy status may have different opinions than the LAR about both recommended and alternate treatment.

Physicians need to be aware that state laws may mandate a hierarchy of people who may give consent by proxy to nonurgent treatment if an LAR cannot be contacted.²⁸⁻³⁰ An example of such a hierarchy is as follows: (1) stepparent, (2) grandparent of minor, (3) adult brother/sister, and (4) adult aunt/uncle of minor.³¹ When a hierarchy is the rule, a person lower on the list generally cannot give consent if a person higher on the list is available. A written power of attorney or affidavit may be needed. Such a document may need to be notarized or witnessed,^{27,32,33} may have a time limit to it,^{27,32-34} and may be needed to supersede this hierarchy.³¹ State law or custodial agreement may not permit a noncustodial parent to consent to treatment of a child. State law may permit foster care licensees and court-appointed guardians to consent, depending on the scope of authority granted by the court and the treatment proposed. Typically, consent to “routine” care is permitted, although the definition of routine may vary among states. Some states have permitted proxies to consent to routine or “ordinary” medical and dental care, which can include radiography, surgery, and anesthesia.³⁵ Other states have excluded surgery, anesthesia, and even psychotropic drugs from the definition of ordinary care.^{27,28,36,37} Immunizations may be excluded from consent by proxy.²⁷ Some state laws

on consent by proxy lack specific guidelines for implementation. In addition, some states provide immunity for physicians from civil and criminal liability if the physician obtains the consent in good faith.²⁷

Even in states without laws defining “ordinary” care, it is important for the physician to recognize and distinguish between appropriate non-LAR consent and inappropriate non-LAR consent. It would be perfectly appropriate, for example, to perform a rapid test for group A streptococcal infection in a patient with a sore throat with consent by proxy. It would be inappropriate, on the other hand, to perform most genetic testing (ie, for Huntington disease) with non-LAR consent.

Minor

A person who is younger than the age of legal competence is a minor by definition. In most states, a person is no longer a minor after reaching 18 years of age.

Current Pediatric Practice

Because there is no legal requirement to provide nonurgent pediatric care to a minor without the consent of an LAR, pediatricians who choose to treat such patients should be aware of potential liability risks. Many pediatricians have not adopted policies to minimize liability risks.³⁸ For example, one-third of pediatricians in an AAP survey responded that they had no set policy regarding treating patients brought in for nonurgent acute care or preventive visits by child care providers. A different national study showed that 64% of pediatricians and family physicians often or always saw adolescent patients for routine health maintenance examinations without a parent present.³⁹ Practices that maintained a specific clinic policy were less likely to see an adolescent for routine care without a parent present than those without such a policy.³⁹

FAMILY LIVING ARRANGEMENTS

Changes in family living arrangements and the use of child care are leading reasons why someone other than an LAR may bring a minor patient in for nonurgent ambulatory pediatric care. The US Census Bureau has described many aspects of family living arrangements. Although the majority of children spend their childhood living in 2-parent families, millions of children in the United States live in homes with other family configurations. More than one-quarter (23.4 million) of all children younger than 21 years lived with only 1 of their parents.⁴⁰ In addition, an increasing number of children (5.4 million [7%]) live with a grandparent. Overall, approximately one-third of all children in the United States do not have 2 parents in the home with legal authority to consent to medical treatment. At the initial visit, pediatricians should ask about the child’s living arrangements. At future visits, changes in living arrangements can be ascertained either through a questionnaire or direct inquiry.

CHILD CARE

Census reports confirm that an increasing proportion of children spend substantial amounts of time in the care of a person other than their parents. According to recent census data, 12.5 million (61%) of children younger than 5 years had some type of regularly scheduled child care arrangement.⁴¹ The time spent in child care was significant, averaging 33 hours per week. A number of arrangements were reported, including care by relatives such as siblings and grandparents, nonrelatives such as babysitters and neighbors, and organized child care facilities such as day care or child care centers, nursery schools, preschools, and Head Start programs.⁴¹ Other children are cared

for by private-duty nurses or nurse's aides, who should be considered as proxies when they bring a child in for medical care.

DOCUMENTING CONSENT BY PROXY

Whenever someone other than the LAR accompanies the child for medical care, it affords an opportunity to assess the relationship between the child and the caregiver, but it precludes face-to-face contact between the pediatrician and the LAR. If it has been anticipated that a caregiver other than an LAR may bring the child to pediatric visits, arrangements should be made for the LAR to provide a written consent by proxy. In general, these documents specify the name of the LAR, the name of the person to whom the LAR's legal authority to consent to the child's medical care has been delegated, and the relationship of that person to the child. Such documentation may need to delineate the extent of the surrogate's authorization (ie, the circumstances, the kinds of medical services, or the specified time period for which the surrogate may provide consent for medical care). State law related to consent by proxy should be reviewed. Signatures may be required, and state law may require that the signatures be notarized.^{27,42} State law may also dictate the specific time period for which a written consent by proxy is valid.^{27,34}

The proxy relationship should be verified and documented periodically. The proxy accompanying the patient should be the same person to whom proxy has been delegated on the aforementioned form. Requesting a dated signature and government-issued photograph identification from the proxy is 1 way to document that verification. Dissimilar signatures may indicate a problem. It should also be verified that the person is authorized to consent for the specific care that

will be provided. The patient's medical record should be flagged to alert all pediatric care team members of situations in which the caregiver cannot provide consent. If the pediatrician has any doubts about the caregiver's capability to provide permission for medical care (eg, lack of maturity, presence of intoxication,⁴³ unclear legal standing, or the inability to understand risk communication, perhaps because of language barriers or limited health literacy), then the pediatrician may need to consider deferring elective care until permission from the LAR can be obtained.

If the pediatrician is uncomfortable with consent-by-proxy arrangements, it needs to be communicated with the LAR as soon as possible. The topic could be broached during early discussions of child care arrangements at prenatal or newborn visits or addressed during medical encounters before the parent returns to employment outside the home. If parents are the caregivers, the pediatrician can explain the importance of the "therapeutic alliance"⁴⁴ between the pediatrician, parents, and patient and emphasize why it is preferable for at least 1 parent to be present during nonurgent visits. Offering extended office hours (evenings or weekends) is another way pediatricians have made it possible for working parents to attend their children's medical appointments.

INITIAL VISIT

Pediatricians should be cautious about proxy situations if they are providing initial care for the child. Medical decisions may be made on the basis of information obtained from the proxy that may not be entirely accurate. Similarly, medical decisions may be made on the basis of follow-up visits that are contingent on the accuracy of the information from the documentation during

the initial visit. Pediatricians who decide to treat children under these circumstances may want to consider "flagging" such charts so that baseline information obtained from the initial visit can be later verified by the LAR. This flagging procedure would be especially important for details such as medication allergy and family history.

UNACCOMPANIED TRAVEL

Consent-by-proxy forms can be useful in other situations as well. Children who travel without their LAR sometimes require medical treatment of a minor injury or illness, which often occurs when children are visiting friends or relatives without their LAR. Although most LARs will sign a proxy consent form when their children go to school or summer camp, few LARs think about sending a signed proxy consent form along when their children leave home for an extended period (eg, a week visiting grandparents). Depending on state law, a child may not be able to obtain routine medical care (which may or may not be defined under state law) without consent to such care by an authorized adult. Pediatricians may encourage LARs to anticipate these problems and to take appropriate action so that their children traveling without an LAR can receive needed nonurgent medical care. When in doubt, pediatricians should consider the best interests of the child in making their decision about rendering care.

CUSTODY AND CONSENT

It is prudent for the physician to inquire about marital status and custody issues when relevant. In most states, parents who are married to each other have an equal right to consent to medical care for the children of that marriage, and the consent of only 1 parent is required for nonurgent pediatric care in

such cases. The physician should not assume which parent has the right to consent for the child when the parents are divorced or legally separated. The right to consent in these situations may be contingent on state law or court order. Some states limit the rights of noncustodial parents and fathers of children born out of wedlock, in which case proof of paternity may not be available, to provide consent to medical care for children.

One of the most difficult situations for securing parental consent for a child's health care occurs when children are used as pawns in marital conflict. "Physical custody" refers to where the child lives. A "residential custodial parent" has sole physical custody, and this parent's home is the child's primary residence. A "noncustodial parent" is usually granted visitation or access rights to the child. "Legal custody," which can be sole (if only 1 parent has legal custody) or joint (if both parents equally share legal custody), refers to parental rights and responsibilities, which include medical decisions and other issues that pertain to the child's general welfare. "Joint custody," when used generically, can either be joint legal custody (parents share nearly equal responsibilities for parenting decisions, such as medical care) or joint physical custody (providing the child with a home). It should be noted that each divorce or legal separation agreement is unique, and specific rights may be granted or denied to a parent, even when the court document describes them as having legal custody of the child. It is important, therefore, to inquire about who has "medical decision-making rights," because it is more directly pertinent to the issue of providing consent for the child's medical care.

Disputing parents can use situations for deciding whether the child should receive nonurgent medical care as an opportunity to spar over parental rights. Generally, if both parents

have equal right to consent to care for their child, the physician need only obtain consent from 1 parent to provide that care. However, there may be situations in which it is not clear whether the pediatrician may seek consent from 1 parent if consent has been refused by the other.⁸ The pediatrician should clarify who has the right to medical information and may specifically ask for a copy of any joint physical or legal custody agreement.⁴⁵ Joint legal custody may be relevant to coordinating medical care, because some joint custody agreements require that both parents need to give consent and be informed about their child's medical needs.

Less commonly recognized is the problem of children visiting a noncustodial parent in another state, especially if that state's law does not permit a noncustodial parent to give permission for the child to receive medical care. These situations are usually unexpected but not unmanageable. For instance, a pediatrician may be puzzled when a family associated with the practice seeks medical care for a child never mentioned or seen previously. It may be a child or stepchild from a previous marriage or relationship who lives in another state and who, while visiting the family, develops a minor illness and requires medical attention. In such situations, pediatricians need to make sure that the adult accompanying the child has the authority to consent to the medical care before treating. Unless a stepparent has legally adopted the child or has been designated as a legally authorized caregiver, he or she may have no legal authority to give consent for treatment.⁸ It is suggested that office staff document the name and relationship of the person providing permission and how his or her authority to do so was ascertained.

OTHER CIRCUMSTANCES

A significant number of children in the United States do not live with either of their biological parents.⁴⁰ Children may be in foster care, under the care of a relative, with a potential adoptive parent, wards of the juvenile justice system, or in other situations in which their caregiver is not a biological parent. The pediatrician should ascertain the exact nature of the relationship, verify the authority of the proxy, and document the legal basis of the proxy-child relationship and the exercise of the informed consent process within that context.

For some children, a request has not yet been made to the court for a guardian to be appointed. For this reason, authority to consent to these children's nonurgent care may be unclear, but a physician should probably not deny them necessary care because of their legal status. The pediatrician should use his or her best judgment in deciding whether to postpone care until a guardian can be appointed or to render the care. If care is provided, careful documentation of the circumstances is recommended. Pediatricians should notify child protective services when a child needs a legal guardian. As noted previously, for children in state custody under a foster care arrangement, there may be restrictions on consent by proxy. Consent for surgery may require a court order.^{28,30}

IMMUNIZATIONS

Although some would debate the logic of requiring informed consent for state-mandated services such as immunizations, it is clear that open dialogue about risk is at the crux of the national Vaccine Injury Compensation Program (VICP).⁴⁶ Vaccine information statements (VISs) were created to meet the informational requirements of the VICP; the VIS alone is not considered

informed consent. The VICP requires that providers distribute a VIS to the patient's legal representative every time a covered immunization is administered. Federal law does not require parental consent for immunizations but instead uses the term "legal representative" as one who may consent. Federal law defines legal representative as a parent or other individual who is qualified under state law to consent to the immunization of a minor. Thus, regarding immunizations, state law controls consent. Non-LAR consent to immunizations may be restricted under some state laws.^{47,48} These state laws may cover procedural requirements (eg, whether consent may be verbal or must be written) or substantive requirements (eg, types of information required). Most states require separate consent for each injection when more than 1 injection is required to complete immunization. Most states require consent for immunization services provided to adolescents.⁴⁹ Some states allow adolescents to provide informed consent for immunization. Unless the law provides otherwise, immunizations should not be given without appropriate consent. The Centers for Disease Control and Prevention Web site contains information on state laws at <http://www.cdc.gov/vaccines/imz-managers/laws>. Each state also has a Department of Health or Bureau of Immunization that can provide beneficial information.

VISs explain the benefits and risks associated with each childhood immunization. They are intended to facilitate, not replace, effective risk communication and proper informed consent between the health care professional and the patient's legal representative. Instructions for using VISs and documentation requirements are available from the Centers for Disease Control and Prevention⁵⁰ and are summarized in the AAP *Red Book*.⁵¹ In addition, the

AAP produces vaccine administration record forms to help pediatricians comply with the VICP documentation requirements. For non-English-speaking patients, VISs have been translated into more than 40 languages. These VISs can be accessed and downloaded from the Immunization Action Coalition Web site (www.immunize.org/vis).⁵²

LANGUAGE BARRIERS TO INFORMED CONSENT BY PROXY

An increasing number of patients and their proxies in the United States have LEP. A similar approach may be needed for patients or LARs with hearing impairment.⁵³ LEP can impede communication, affect the quality of care, and become a major future medical malpractice issue relating to informed consent.⁵⁴ These issues will only be compounded in scenarios that involve consent by proxy. Various federal and state laws and regulations apply to individuals with LEP, including the Americans with Disabilities Act,⁵⁵ the Rehabilitation Act of 1973,⁵⁶ title VI of the Civil Rights Act,⁵⁷ and HIPAA.¹⁵ More than 60 million people in the United States speak a language other than English in the home.⁵⁸ If the proxy does not speak the same language as the pediatrician, it may be difficult to obtain informed consent.⁵⁹

Although patient education materials and consent forms can be developed in various languages for common procedures that require informed consent, it would be unwise to rely exclusively on written informed-consent methods. Translations that are accurate according to the textbook language may not be appropriate to the comprehension level of the reader. Most pediatricians report the use of untrained interpreters to communicate with patients and families with LEP, not only in smaller and rural practices but also in states with higher

proportions of people with LEP.⁶⁰ If the pediatrician suspects that language barriers may compromise the communication between him or her and the proxy necessary for informed consent, other steps may need to be taken. Health care professionals who participate in federal health programs (eg, Medicaid, state Children's Health Insurance Program, TriCare, Medicare) are expected to meet requirements for accommodating patients with LEP, which may involve qualified translators other than family members.⁶¹ Some patients with LEP may be eligible for language assistance if their health care provider participates in a federal government program.⁶² Health care providers may be placing themselves at risk of liability if proxies have problems understanding them because of a language barrier. Malpractice lawsuits related to the issue of LEP have been based on both negligence and inadequate informed consent.^{63,64} It is preferable to have someone who is medically knowledgeable explain the illness, treatment options, and known risks and benefits in the proxy's own language. The practice should record and retain on file the name, address, and background of the translator. Translators should be instructed that they are to communicate the caregiver's answer directly, which is vital for conveying to the pediatrician whether the respondent's answer indicates an understanding of the elements needed for informed consent and whether an agreement has been reached as to the medical treatment. It is not advisable to use children (eg, the patient or an older sibling or relative) as translators for informed consent. The use of adult family members as translators may result in incorrect history because of concerns about their desire to not disclose personal information. Certain scenarios could violate section 601 of title VI of the Civil Rights Act, which states that no

person shall “on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”⁶¹

PROBLEMS WITH PROXIES WITH LIMITED HEALTH LITERACY

Modern health care is very complex, and many patients and parents have poor health literacy, defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”⁵⁹ Indeed, nearly 9 of 10 adults have a hard time understanding routinely available health information,⁶⁵ and the Institute of Medicine has estimated that 90 million American adults lack the literacy skills to effectively use the health care system in this country.⁵⁹ Informed consent works best when efforts are made to help proxies understand the health information that is being conveyed to them.

SUMMARY

When the care provided is done so in the best interest of the child, the liability risk is generally low, even without appropriate consent. This risk is likely to be higher in certain situations, such as in those that involve immunizations, language barriers, limited health literacy, and the initial visit. Medical practice is primarily regulated by the states, and it is essential that pediatricians are aware of the medical consent laws where they practice. Pediatric practices need to anticipate that situations that involve consent by proxy can occur for a variety of reasons. Policies should be developed that promote good, informed decision-making and risk management. Care should be taken to make sure that such policies meet

applicable laws without blocking access to necessary but nonurgent health care. Pediatricians have sought ways to accommodate the diverse living and working arrangements of their patients’ families. Many pediatricians are working parents themselves and know well the challenges of family life. Developing a legally sound office policy on consent by proxy is essential for maintaining efficient office operations and strong physician-patient relationships.

IMPLEMENTATION SUGGESTIONS

1. Determine whether the practice will see minor patients without an LAR present. It is usually best if all physicians within the practice adopt the same policy; otherwise, problems can occur during coverage situations.
2. If the practice’s decision is to not provide nonurgent care to patients without an LAR present, then the policy for the office and an information sheet explaining it should be provided to patients and their LAR. The policy should also be made clear during contacts with new or prospective patients.
3. If the practice decides to provide nonurgent care to patients accompanied by someone other than their LAR, then it should establish a policy and procedural guide for the office as well as a patient information sheet that explains the policy. This statement may spell out the LAR’s responsibilities in providing and documenting his or her consent-by-proxy arrangement. The pediatrician should educate office staff members, particularly those involved in telephone triage and scheduling appointments, so that they understand the policy and their responsibilities, including verifying the identity of the proxy. In addition, the pediatrician and practice should determine the consent-by-proxy policy of

ancillary services that may be used during an office visit, such as radiology or laboratory services.

4. It is advisable to create a template form to be used in cases in which individuals other than LARs may be expected to accompany a child to the office. Suggested items to address include the following:
 - a. Who has the legal right to delegate consent to health care decisions for the child?
 - b. To whom can the power to consent to health care for a child be delegated?
 - c. In what circumstances can the power to consent to health care for a child be delegated (eg, while child is vacationing out of state with grandparents or while parents are traveling overseas and the child remains home with the nanny)?
 - d. For which services (eg, radiology, preventive care, immunizations, laboratory tests) can the power to consent to health care for a child be delegated?
 - e. With what limitations can the power to consent to health care for a child be delegated? (For example, the proxy may consent to treatment of a child’s sprained ankle but may not be authorized to take the child to the visit with the orthopedic surgeon.)
 - f. How is authorization of proxy consent verified and documented?
 - g. When or how often should information on proxy consent be updated?
5. The proxy relationship should be verified and documented periodically. In addition, when the office or pediatrician does not know the proxy personally, photo identification, such as a driver’s license, may be required.

6. Establish an office procedure for providing and documenting informed consent for proxies with LEP, hearing impairment, and limited health literacy. Similarly, information sheets related to office policies should be accessible for proxies with LEP and limited health literacy.
7. A number of state and federal laws affect the ability to give consent by proxy.^{27,30} Pediatricians need to be aware of these laws (available at www.plol.org). In addition, it is advisable to have legal counsel review office policy and supporting documents to promote compliance with applicable laws.
8. It is recommended that informed consent, including consent by proxy, be included in residency training and continuing medical education. Such educational efforts have been effective in improving knowledge and attitudes about informed consent.⁶⁶
9. When in doubt about informed consent in a proxy situation, pediatricians should use discretion in deciding whether to treat and should base the decision on the best interests of the child.

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ABBREVIATIONS

AAP: American Academy of Pediatrics

HIPAA: Health Insurance Portability and Accountability Act

LAR: legally authorized representative

LEP: limited English proficiency

VICP: Vaccine Injury Compensation Program

VIS: vaccine information statement

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