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# HEALTHCARE TREATMENT DECISION-MAKING GUIDELINES FOR MINORS

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## 1. Prologue

The Midwest Bioethics Center (now the Center for Practical Bioethics) convened a task force late in 1991 to consider the implications of the Patient Self-Determination Act for the healthcare of minors because the act did not include children. In the process, this group decided to expand its focus to healthcare treatment decision making for minors. The group decided that the primary focus of its work should be on the ethical issues relating to the participation of children in decision making regarding their healthcare and that legal aspects of these issues would not dominate its work.

To accomplish this, the task force agreed on a new model for healthcare decision making involving minors. In constructing this new conceptual model, the task force assumed that the model should reflect the obvious fact that there are at least three categories of minors with respect to their capacity to participate in treatment decision making:

- minors without the capacity to participate in decision making in any meaningful way, for example, infants, toddlers, and most preschool aged children;
- minors with a developing capacity to participate in decision making; for example, elementary school aged children;
- minors who have achieved the capacity to make most healthcare decisions; for example, mature minors, emancipated minors, and most senior high school-aged young adults.

The conceptual model the task force is proposing acknowledges and attempts to honor children in all three categories. There are three fundamental aspects to the model we are proposing.

The first and most innovative component of the model is child assent. We believe strongly that a model for healthcare decision making involving minors must include a recognition of the developing capacity of minors for rationality, autonomy, and participation in decision making and their evolving sense of self and life story. Assent is the free expression of a child's willingness to undergo a specific healthcare treatment based on the child's knowledge and understanding.

The elements of this concept are outlined below (see Section 2.3). The Task Force proposes that healthcare providers are ethically obligated to solicit the assent of their minor patients who are capable of participating in treatment decision making but have not yet fully developed decisional capacity (see Section 2.5). In addition, healthcare providers treating minors with evolving capacity are also obligated to obtain informed parental/guardian permission for healthcare treatment for their children.

The second component contained in this model applies to the role of parents/guardians in healthcare decision making for their minor children. Although the law in most jurisdictions recognizes a parental right to consent to their children's healthcare treatment, the task force believes that the concept of parental consent raises serious ethical problems. We believe that the concept of parental consent or the related concept of a parental right to refuse consent are incompatible with the ethical obligations and responsibilities of healthcare providers to their minor patients. In lieu of parental consent, the task force proposes the adoption of the concept of **informed parental/guardian permission** (see Section 2.13).

The third component is our proposal that the age of decision making for healthcare treatment

should reflect the fact that many minors achieve decisional capacity at much earlier ages than is recognized legally. *We propose that all persons with decisional capacity have the right to make healthcare treatment decisions, that is, are capable of engaging in the informed consent process.*

We are aware that the implementation of this model poses many challenges for healthcare providers, parents, and healthcare institutions. This document is not intended to be a sample policy or procedure. Rather, it is intended to challenge existing ways of treating children and to provide a conceptual framework for healthcare providers open to doing so. Ultimately, we are committed to the pursuit of a *shared* decision-making model — one that respects the important and distinct roles of children, parents, and providers in healthcare decisions.

**1.1. Process:** The task force was comprised of pediatric healthcare providers, including pediatricians, nurses, social workers, child psychologists, child psychiatrists, chaplains, and patient representatives; also included were clinical ethicists, healthcare lawyers, risk managers, community representatives and staff from Midwest Bioethics Center. In total nine organizations had representatives on the task force.

Task force members met on a monthly basis for nearly three years. Meetings consisted of three hours of discussion fostered by relevant articles that had been distributed ahead of time. Following each meeting Center staff members met and wrote a summary of the discussion which was circulated along with additional articles to task force members prior to their next meeting. Each meeting began with a review and critique of written work provided by staff, and was followed by a rewriting of the document. Ultimately, the draft document created by the Center staff became the mechanism through which the task force recorded its progress. It also provided a substantive outline for this guideline document.

Early in the work of the task force, task force members realized we could not work in isolation. Initially, we approached children's specialty hos-

pitals around the United States and asked for a copy of their "patients rights statements." Next, we began to distribute our draft document to a variety of organizations concerned with the health and well-being of children. We wish to express appreciation to all who provided us with critical feed-back; however, we are especially appreciative of the American Academy of Pediatrics Committee on Bioethics, the National Association of Children's Hospitals and Related Institutions (NACHRI) and the Association for the Care of Children's Health (ACCH) for their input.

As we began to explicate a statement of rights regarding healthcare treatment decisions for minors, we realized that an important voice was missing from our discussion—the voice of minors themselves. To involve them in our work we decided to present the rights statement to focus groups of minors between the ages of seven and fourteen. These groups were held in a variety of settings and included both healthy children and children challenged by disease and illness. Focus groups took up to two hours, and all the children involved seemed engaged and willing to help. Their help with language that is understood by children was particularly helpful, but conversations about more substantive issues were lively as well. The concern of some task force members as to whether or not younger children would be able to deal with the document's conceptual underpinnings was alleviated when a nine-year-old focus group participant named Sydney defined rights as "things that make it so that everyone is treated fairly and no one is treated badly." (One focus group member asked her mother for a student membership to Midwest Bioethics Center and became the Center's youngest member.)

## **2. Definitions**

The definitions listed below are key to understanding this document. Therefore, we have placed them at the beginning and encourage readers to familiarize themselves with them before proceeding. In particular, special attention should be given to the definitions of "decisional capacity," "child assent," "informed consent," and "informed parental permission." The definition of "family" is

also important. Task force members have chosen to define this term in a broader way than usual in order to accommodate the realities of the world in which children live.

2.1. **Advance directives:** this term may refer to any directives, either oral or written, made in advance of losing decisional capacity by an individual regarding his or her healthcare treatment wishes. Written advance directives may include living wills, healthcare treatment directives, and durable powers of attorney for healthcare. Although advance directives made by minors may not be legally binding, they are helpful communication documents.

2.2. **Best interests:** this term applies to decisions made for persons without the ability to make treatment decisions; surrogates making such decisions should choose so as to promote the patient's interests as they would be conceived by reasonable persons when in the patient's condition.

2.3. **Child assent:** assent is the free, uncoerced expression of a child's willingness to undergo a specific healthcare treatment based on the child's knowledge and understanding. The process for soliciting assent includes

- assisting the minor to the fullest extent of the child's ability to comprehend or understand the nature of his or her condition;
- disclosing to the minor the nature of a proposed treatment and what the child is likely to experience in undergoing it;
- soliciting the minor's free and uncoerced willingness to accept the proposed treatment.

2.4. **Conflict Resolution:** a model of shared decision making must be supported by a variety of mechanisms for resolving ethical conflicts between the various persons involved. These mechanisms include additional medical consultation, case management conferences, and efforts to mediate the conflict with assistance from patient representatives, social workers, pastoral care providers, case managers, clinical ethicists, and others. In addition, most healthcare providing organizations have ethics committees that may be of assistance.

As a last resort, conflict resolution may require appeal to the courts.

2.5. **Decisional capacity:** an individual with decisional capacity has the ability to make a specific decision, that is, the ability to understand relevant information, to reflect on it and communicate the decision (verbally or nonverbally) to providers. Decisional capacity can also be understood as the ability to participate in an informed consent process.

2.6. **Do not resuscitate (DNR):** a physician's order preventing a patient from undergoing cardiopulmonary resuscitation where resuscitation has been determined to be either futile or inconsistent with the patient's values, wishes and goals.

2.7. **Emancipated minor:** this term applies to minors who have legal authority for making healthcare treatment decisions. It applies to three categories of minors: (1) court ordered emancipation (e.g., teenagers living apart from their parents who petition the court to be treated as though they have reached legal majority), (2) statutorily defined emancipation (e.g., married minors or minors who are parents), or (3) medical emancipation (e.g., minors seeking treatment for a specific medical condition such as a sexually transmitted disease).

2.8. **Expression of healthcare preference:** a communication by which a patient provides information that he or she hopes will help another person make healthcare decisions on his or her behalf.

2.9. **Family:** the person or persons who play a significant role in the patient's life. This term includes individuals who may or may not be legally related to the patient.

2.10. **Healthcare:** the task force uses this term in an inclusive sense to include mental health services, pastoral care services, and other similar services.

2.11. **Healthcare provider:** a generic term used in this document to apply to all those involved in the direct provision of care to patients including,

physicians, nurses, social workers, therapists, chaplains, and others.

2.12. **Informed consent:** informed consent is the means by which a person with decisional capacity, or his or her personally designated surrogate, authorizes treatment. Consent must be given voluntarily and without coercion based on a clear understanding of at least the following:

- the nature of the patient's condition and prognosis;
- the nature and purpose of the proposed treatment; and
- the benefits, risks and burdens of proposed treatment alternatives or nontreatment.

2.13. **Informed parental permission:** a process by which the parents or guardians of minors grant or deny permission to the provision of recommended healthcare interventions for their children or wards.

- Healthcare providers have the obligation to obtain informed parental permission prior to healthcare interventions (except in emergency situations).
- Informed parental permission involves all the "informational" elements of informed consent.
- Parents may give permission or refuse to give permission to initiate or terminate healthcare treatments when minors are unable to participate in decision making.
- Informed parental permission must be coupled with the assent of the child when decisions involve a child with a developing capacity for decision making (see Section 2.3).

2.14. **Mature minor:** a minor who is believed by a healthcare provider to have decisional capacity and is allowed to authorize or consent to a specific medical treatment.

2.15. **Minor:** a person from birth to the age of legal majority.

2.16. **Parent:** a person who is primarily responsible for the care of a minor. This individual may or may not be the legal parent or the legal guardian of the minor.

2.17. **Patient Self-Determination Act (PSDA):** federal legislation enacted in December 1991 which requires all hospitals, nursing homes, home care agencies, hospices and HMOs that receive reimbursement from Medicare or Medicaid to inform patients upon admission of their right to choose and refuse any medical or surgical intervention and to make advance directives within the confines of state law.

2.18. **Surrogate:** the person who makes decisions for the minor when the minor lacks capacity to do so. Appropriate surrogates may include

- the minor's parent or parents;
- an individual designated by a minor with decisional capacity; or a
- court appointed guardian.

2.19. **Treatment:** a general term for evaluation, testing, diagnosis, consultation, and therapeutic interventions.

### 3. Problems

Task force members began their work by going through a process of problem clarification. Reading through the list of problems identified reveals the evolutionary thinking which caused members of the task force to shift their attention from the relevance of the PSDA to mature and emancipated minors (their original task) to the larger questions associated with the role of minors in healthcare treatment decision making. Although stated in the declarative, each of the following statements contains an implied question. Addressing these issues revealed the inadequacy of the current model based on legally defined age parameters, and ultimately led task force members to propose this new model.

3.1. Many states have statutorily defined "adult" to mean a person at least eighteen years of age; legislation regarding advance directives is tied to these definitions.

3.2. It is unclear whether minors who have been legally emancipated by court order or by statute should be provided information and be allowed to complete advance directives under the PSDA.

3.3. Some minors with certain medical conditions are allowed to seek medical treatment without parental involvement. It is not clear whether or not “medically emancipated minors” should be provided information about and allowed to complete advance directives.

3.4. In many clinical situations, minors are treated as having the capacity and legal authority to provide consent to specific medical treatments. It is unclear whether or not “mature minors” should be provided information about and allowed to complete advance directives.

3.5. Generally, the legal system does not yet recognize minors as independent decision makers regarding their healthcare.

3.6. A persistent disagreement between a legally competent parent and a minor regarding treatment decisions is not acknowledged as a problem by our legal system since the parent usually has the legal power to authorize medical treatment.

3.7. Many providers of care to minors believe they have an ethical duty to involve minors, to the extent of the minor’s capacity, in all healthcare decision making—including decisions regarding life sustaining treatment. However, such involvement of minors is neither routine nor always recognized as an ethical obligation of healthcare providers. As a result, providers who act on this perceived duty are not routinely supported in doing so.

3.8. Mechanisms for documenting the participation of minors in healthcare decision making have not been developed. Although assent of minors is routinely solicited and documented for children who are participating in human subjects research, assent is neither routinely solicited nor documented in most clinical contexts.

#### **4. Assumptions of the Task Force**

Task force members spent a significant amount of time explicating their working assumptions

which became an important touchstone. Time and again as new ideas were proposed or solutions recommended, they were juxtaposed against this list to see if they were consistent with these fundamental notions. When it was found that they were not, they had to be reconsidered and reconciled. Sometimes the idea was rejected because it was inconsistent with our assumptions; other times, the assumption was restated. In those instances the document had to be reviewed to check the effect of the amendment on prior conclusions.

4.1. All persons with decisional capacity, regardless of age, have the right to make healthcare treatment decisions.

4.2. Decisional capacity is not necessarily determined by a person’s age (see Section 7.4).

4.3. Parents are the primary guardians of the rights, welfare, and health of their minor children.

4.4. Policies and practices must incorporate the recognition of cultural diversity, and the strengths and individuality of families. Families should be regarded as having a wide range of goals, beliefs, and values which may influence treatment decisions.

4.5. Children are not the property of their parents, and parents do not have absolute authority to make healthcare treatment decisions on their behalf.

4.6. Minors have moral status and legal standing independent of their parents. The ethical injunction to respect persons applies to minors of any age just as it does to adults.

4.7. Healthcare providers have an ethical and legal obligation to act in the best interest of their patients.

4.8. Providing care to minors requires providers to be sensitive to the fact that young children experience the world very differently from adults. Therefore, any attempt to implement these guidelines and the spirit of PSDA will require a flexible, developmentally appropriate, and individualized approach.

4.9. Encouraging minors, especially minors with chronic illness and terminal illness, to express themselves through discussion, drawing, or writing about their illness may be an important component of their treatment.

4.10. When minors lack capacity to make or communicate treatment decisions (e.g., infants, preschoolers, and some cognitively impaired children), such decisions are commonly based on what is called a “best interest of the child standard.” In our society, it is commonly presumed that the child’s parents are the appropriate surrogate decision makers. As such, parents should be allowed to determine which course of treatment is in the best interests of their child. This presumption is subject to challenge in cases where the course of action chosen by the parents is clearly contrary to providers’ judgments about the best interests of the child.

4.11. Some minors have a developing capacity for rationality, participation in decision making and autonomy (e.g., elementary school aged children). Their capacity is not so fully developed as that of mature minors. However, since they are not completely lacking in decision making capacity, respect for such minors requires explicit acknowledgment of their role in healthcare decision making and treatment.

4.12. In the case of emancipated or mature minors, the ethical and legal presumption of capacity should govern. A clear demonstration of lack of capacity is necessary to override the decision of an emancipated or mature minor.

4.13. Healthcare providers should avoid coercion, deception, and force in caring for minors. Force should be seen only as a last resort to be used in emergency situations or where all reasonable attempts to obtain assent of the minor have failed. Minor patients are owed an explanation and justification in any instance where an intervention is to be—or has been—undertaken against their expressed wishes.

## 5. Goals of the Task Force

The following list of goals seems inordinately long; however, as stated in the Prologue, the goals of the

task force changed over time. At the conclusion of their work, task force members were in agreement that their primary goal was to promote a model of healthcare decision making which honors minors and involves them to their fullest capacity in healthcare treatment decisions while respecting the unique social relationship of minors to their parents and healthcare providers.

The goals of the task force are to

5.1. Promote discussion about the capacities and moral standing of minors to participate in healthcare treatment decision making.

5.2. Give special consideration to withholding/withdrawing life-sustaining treatment decisions in the care of minors.

5.3. Consider the implications of the PSDA related to minors.

5.4. Attempt to identify consensus about the role of minors in treatment decision making among members of the task force which includes parents, physicians, nurses, social workers, chaplains/pastoral care professionals, child psychologists, attorneys, ethicists, and others.

5.5. Develop a model for healthcare decision making involving minors which both respects the important role of the minor and allows for appropriate involvement of parents/guardians, healthcare providers, and healthcare institutions.

5.6. Provide recommendations for the resolution of conflict when it persists among minors, their parents, or healthcare providers.

5.7. Include minors and parents in the development of the model.

5.8. Develop a model that supports families and their values as they interface with the healthcare system.

5.9. Share the results of this work with healthcare providers and other providers involved with the care of minors.

5.10. Discuss and explore with the broader community the many legal, ethical, and public policy ramifications of this document.

## 6. Children's Rights: Information for Minors, Parents, Providers, and Institutions

Most rights statements reviewed by the task force were actually written for parents rather than for minor patients. Our efforts have been to provide a statement of rights directed to and understandable by children coupled with information for parents.

The task force assumes that the information in Sections 6.1., 6.2., and 6.3. will be used to prepare an informational brochure which will be distributed to children and their parents when a child is admitted into a healthcare program or facility. The task force recognizes that a written statement of rights is an inadequate vehicle for informing and educating minors about their rights. The task force assumes that a written text will be supplemented by materials more suited for use with children such as children's books, videos, and other educational materials.

In Section 6.4., the task force describes the duties and obligations of healthcare providers and organizations necessary to support the rights of patients and the important role of parents in decision making. Readers will notice that this section does not contain a statement of the responsibilities of minors and their parents although patients' rights statements are often coupled with statements of patient responsibilities. Members of the task force discussed this at length but ultimately decided that such a statement may tend to undermine its basic effort to empower children and their families in the healthcare context.

### 6.1. A Patient's Rights Statement for Patients with Developing Capacity.

(This statement is written for use primarily with minors who are able to read or to understand its contents if it is read to them. Minors who are infants or preschool age will not be able to understand the basis of this statement and depend on their family and healthcare providers to protect their rights. This statement is an inadequate statement of the rights of minors who have decisional capacity [see Section 6.2.]

Please read this list of rights. If you need help reading it or need to have some of the words explained to you, ask your mom or dad, someone from your family, or any of the people taking care of you.

This is a list of rights you have as a patient here at \_\_\_\_\_:

6.1.a. The right to be told whatever you need to know to help you understand why you are here.

6.1.b. The right to be told in a way you can understand about anything that is going to be done to you while you are here. And to be told truthfully what it may feel like to have those things done.

6.1.c. The right to be given answers in ways you can understand to any questions or worries you have about your treatment.

6.1.d. The right to tell your family, doctors, nurses, and other people taking care of you what you think and feel about your treatment and what is being planned for you.

6.1.e. The right to get angry, cry, or say what you don't like about what is happening to you.

6.1.f. The right to ask for special things or people who are important to you.

6.1.g. The right to know that if you are scared, in pain, or hurting, the people taking care of you will always try to help you.

6.1.h. The right to help your family and the people taking care of you decide what will be done for you.

6.1.i. The right to be given help to solve a disagreement if you and your family or you and the people taking care of you don't agree about what should be done for you.

6.1.j. The right to agree or disagree to anything that is going to happen to you. If you tell the people taking care of you that you disagree, you have the right to know that nothing will be done to you until the people taking care of you talk to you about your worries and questions.

6.1.k. The right to know that nothing will happen to you that you do not want unless your family

and the people taking care of you agree that you need to have it done.

6.1.l. The right to know that when the people taking care of you touch your body, they will tell you what they need to do, be gentle, and do it in a private way.

6.1.m. The right to know that what people taking care of you learn about you will not be told to people who do not need to know.

6.1.n. The right to be able to talk freely with the people taking care of you and to know that what you say will not be told to others, including your family, unless it is important to your care.

6.1.o. The right to know if your care is part of an experiment. You can agree or not agree to be part of these experiments or stop being part of any experiment.

6.1.p. The right to have your family with you as much as possible if you want them to be. When it is not possible, the people taking care of you will explain why they can't be with you.

6.1.q. The right to know that nothing done to you by your doctors, nurses, or the other people taking care of you is being done to punish you.

6.1.r. The right to have the people taking care of you teach you and your family all you need to know about your healthcare so that you can take care of yourself at home.

6.1.s. The right to have a "special safe place."\* You will be told about this special place and you and your family will be shown where it is.

6.1.t. The right to be treated as a growing person and to have times and places to play and to learn while you are here.

6.1.u. The right to read or have this list of rights read to you and explained to you as often as you want.

## 6.2. A Patient's Rights Statement for Minors with Decisional Capacity:

(This statement is written primarily for use with minors who are believed to have capacity to make most healthcare decisions.)

We need you to participate in decisions about your healthcare. By talking with your care providers and actively participating in planning your care, you will help to ensure that the care you receive reflects your dignity and is in keeping with your desires and values. You are being treated as a person who is capable of making your own healthcare decisions; therefore, you are being given this information regarding your rights. However, you should be aware that in certain circumstances your ability to act on these rights may be limited by laws, regulations, or policies of the hospital. If acting on any of these rights conflicts with the desires of your parents or guardian, you and your parents or guardian will need to work with members of the hospital staff to try to resolve the conflict.

As a patient at \_\_\_\_\_, you have the right to

6.2.a. Be treated with respect by all personnel.

6.2.b. Have your expressed personal, cultural, and spiritual values and your beliefs considered when treatment decisions are made.

6.2.c. Have a physician primarily responsible for your care and to know who that person is.

6.2.d. Know the name and professional status of care givers providing service to you.

6.2.e. Receive complete and current information concerning your diagnosis, treatment, and prognosis in terms you can understand.

6.2.f. Have access to your medical records and to an explanation of all information contained in your records.

6.2.g. Have any proposed procedure or treat-

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\* Most organizations that provide care to minor patients provide "safe" areas where diagnostic or treatment procedures are not performed on patients, for example, in classrooms or playrooms.

ment explained in terms you can understand. Information you may want includes but is not limited to

- a description of the nature and purpose of the procedure or treatment;
- the benefits and risks;
- problems related to recovery;
- the likelihood of success;
- any alternative procedures or treatments (including forgoing specific treatments); and
- costs.

6.2.h. Participate with your healthcare providers in planning your healthcare treatment.

6.2.i. Accept or refuse any procedure, drug or treatment and to be informed of the possible consequences of any such decision.

6.2.j. Express your preferences about treatment in advance so that they may be respected should you lose the ability to make treatment decisions. If you choose to write out your wishes, you will be provided information about how to complete advance directives.\*

6.2.k. Appoint a person to make healthcare decisions on your behalf in the event you lose the capacity to do so.

6.2.l. Have personal privacy. Discussion of your care, consultation, examination, and treatment will be conducted discreetly.

6.2.m. Have all communications and records related to your care kept as confidential as possible.

6.2.n. To be treated fairly regardless of race, color, religious belief, national origin, citizenship,

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\* In some jurisdictions advance directives made by minors may not be legally binding; however, the task force believes they are important communication documents which should always be considered and honored whenever possible.

age, gender, sexual orientation, marital status, disability, economic status, or source of payment.

6.2.o. Receive services in response to reasonable requests that are within the institution's capacity and mission.

6.2.p. Be provided supportive care including appropriate management of pain, treatment of uncomfortable symptoms, and support of your psychological and spiritual concerns and needs.

6.2.q. Receive assistance in obtaining consultation with another physician.

6.2.r. Request consultation from the institutional ethics committee and other appropriate sources regarding ethical issues surrounding your care.

6.2.s. Be transferred to another facility only after having received complete information and explanation concerning the need for and alternatives to such a transfer. (The facility to which you will be transferred must first accept the transfer.)

6.2.t. Consent to or to refuse care that involves research, experimental treatments, or educational projects.

6.2.u. Complain about your care without fear, have your complaints reviewed, and, when possible, resolved.

6.2.v. Be informed by a responsible care provider about continuing healthcare requirements and alternatives for meeting those after you are discharged from the healthcare providing institution.

6.2.w. Examine your bill and receive an explanation of the charges.

6.2.x. Be informed of the healthcare providing organization's policies, procedures, rules, and regulations applicable to your care.

If you have questions regarding these rights or wish to voice a concern about a possible violation of your rights, you may contact \_\_\_\_\_.

### **6.3. Information for Parents**

(This statement is intended to be used to develop an informational brochure or educational

materials to be provided to parents of minor patients. It is intended to complement the patients' rights statement provided to their child. This document should also be provided to guardians of children who are wards. The document should be translated when feasible. In most facilities it would be distributed and explained by the admitting nurse.)

If your child lacks the ability to participate meaningfully in decision making, we assume that you and your child's healthcare providers will share responsibility for both respecting your child's rights and making treatment decisions for your child. If your child is able to read, a statement of rights will be given to him or her. Please read it and discuss it with your child.

When you admitted your child to the healthcare providing institution, you gave us your general permission to take care of your child. However, you may be asked to give your specific permission for certain tests and treatments such as surgical procedures.

We recognize that this may be a time of special stress in your family. We want to be as supportive as possible of the important role you play in your child's life. We also want you to know that our primary concern is to provide care in a manner which respects and promotes the rights and welfare of your child.

The following information is provided to assist you to understand your role in caring for your child while at \_\_\_\_\_.

6.3.a. You and your child will be treated fairly regardless of race, color, religious belief, national origin, citizenship, age, gender, sexual orientation, marital status, disability, economic status, or source of payment.

6.3.b. You have the right to know the names of physicians, nurses, and staff members responsible for your child's care.

6.3.c. You have the right to be told in language and terms you can understand the nature of your child's illness and the probable outlook for children with that illness.

6.3.d. You will be asked to provide any information that may assist your child's healthcare providers to understand the nature of your child's illness.

6.3.e. When possible, at least one member of your family will be allowed to stay with your child, including spending the night. If you and your child agree, you may stay with your child during most treatments.

6.3.f. You have the right to information about tests or treatments that are not a routine part of your child's care. Information you may want includes but is not limited to

- a description of the nature and purpose of the procedure or treatment;
- the benefits and the risks;
- the problems related to recovery;
- the likelihood of success;
- any other possible procedures or treatments (including forgoing specific treatments); and
- the costs.

6.3.g. You are encouraged to share your concerns and to ask questions about these tests and treatments.

6.3.h. Except in an emergency, you will be asked to give permission for nonroutine tests and treatments. In addition, your child will be asked to agree to undergo them.

6.3.i. In case of disagreement regarding a proposed test or treatment, you will be given help to resolve the disagreement. Help may include talking with another healthcare provider, a mental health professional, a social worker, or a chaplain. You may also request help from our ethics committee.

6.3.j. If disagreements about treatment decisions cannot be resolved, you have the right to ask that another doctor or nurse take care of your child, or that your child be transferred to another healthcare providing institution. The institution and the physician taking care of your child will assist you to do

so. If transfer of your child cannot be accomplished or your child's healthcare providers oppose transfer, this conflict may require legal resolution. In this case, you will be provided notice of a pending legal procedure and be given information to help you obtain legal counsel.

6.3.k. You may take your child home before planned discharge if you choose to do so. If your child's healthcare providers think that doing so would place your child in serious danger, they may seek legal permission to keep your child in the healthcare providing institution. If this occurs, you will be notified that a court order to keep your child in the institution is being sought and you will be given information regarding how to obtain legal counsel.

6.3.l. Give permission or refuse to give permission for care that involves research, experimental treatments or the education of healthcare providers.

6.3.m. You have the right to examine your child's bill and to receive an explanation of it.

6.3.n. You have the right to have access to your child's medical records and to an explanation of all information contained in your child's records. Because your child has been told that information about him or her will be kept in confidence, your child will be asked to agree to your seeing these records. If there is disagreement, help will be given to you and your child to resolve the disagreement.

6.3.o. Unless release of medical information about your child is required by law, your permission must be obtained before information can be released to any third party.

6.3.p. You have the right to complain about your child's care, to have those complaints reviewed and resolved, when possible. Your complaints will not affect your child's care.

6.3.q. If you have any questions regarding this document, your rights, or the rights of your child, you may contact \_\_\_\_\_ by calling \_\_\_\_\_.

## **6.4. Duties and Obligations of Healthcare Providers and their Organizations**

(This text is intended to be used in a variety of ways: to educate healthcare providers, to comply with the educational aspect of the PSDA, to orient new staff members, and to develop an organizational code of ethics as required by the Joint Commission for the Accreditation of Healthcare Organizations.)

\_\_\_\_\_ (name of facility) has the duty/obligation to

6.4.a. Treat patients and their families with respect and to provide competent healthcare services.

6.4.b. Provide services in a manner that does not discriminate against persons because of race, color, religious belief, national origin, citizenship, age, gender, sexual orientation, marital status, disability, economic status, or source of payment.

6.4.c. Provide an environment which is developmentally appropriate and accessible to persons with disabilities.

6.4.d. Provide and explain written information to children and their families about their rights in language and terms they can understand.

6.4.e. Protect and advocate for the rights of children and their families.

6.4.f. Acknowledge and support the role of the minor's family as the primary guardian of the rights, welfare, and health of their minor children.

6.4.g. Protect confidentiality of minors and their families.

6.4.h. Provide care that respects the privacy of minors and their families.

6.4.i. Offer spiritual, emotional and psychological resources to meet the culturally diverse needs of children and their families.

6.4.j. Encourage cooperation and collaboration among minors, their families, and healthcare providers.

6.4.k. Communicate openly and honestly with minors and their families.

6.4.l. Obtain informed consent of the minor or parental permission when appropriate; and to solicit the assent of the child when appropriate.

6.4.m. Provide a means for conflict resolution and assure its accessibility to both minors and their families.

6.4.n. Notify minors and their families in the event that the institution intends to undertake any legal action to protect the interests of the child and to provide information to families in obtaining legal counsel in such circumstances.

6.4.o. Assist patients in the completion of advance healthcare treatment directives when appropriate.

6.4.p. Provide both patients and families with the educational opportunities they require to participate actively in decision making and healthcare.

6.4.q. Protect patients, their families, and staff by creating a safe environment.

6.4.r. Assist patients and their families to find the financial resources required for healthcare expenses.

6.4.s. Develop written policies and procedures that address the ethical considerations involved in patient care, such as, patient rights, informed consent and refusal of consent, withholding/withdrawing life support, and/or do-not-resuscitate orders (DNR), among others.

## 7.0 Decision-Making Guidelines

The roles of children, parents, providers, and healthcare institutions in decision making change significantly as the child develops from infancy to adulthood. The task force has chosen to provide three models for decision making:

- One for decision making involving minors without decisional capacity;
- The second for minors with a developing capacity to participate in treatment decision making, and;

- A third for minors who have developed decisional capacity.

These guidelines are intended to provide an ethical framework for decision making. The task force acknowledges that existing laws and regulations may not support this framework. Legislative change may be required before this framework can be completely implemented. Healthcare providers are encouraged to be familiar with existing state law and regulations.

**7.1. Minors without decisional capacity** (i.e., infants, very young children, and minors with cognitive impairment)

7.1.a. Role of the Child: since these minors have very limited capacity to participate directly in decision making, their role is also limited in decision making. Parents and providers should make every effort to “hear” and respect efforts by such children to communicate their treatment preferences both verbally and nonverbally.

7.1.b. Role of the Parent: parents are primarily responsible for the health and well-being of their child. In the decision-making process, parents should:

- both obtain and provide necessary information;
- work with healthcare providers to determine which treatment options pose the least risks, harms, and burdens to their child and which options provide the greatest possibility of benefit, and attempt to balance the risks and benefits of various options;
- promote the best interests of their child;
- participate in conflict resolution when there is disagreement about what treatment is in the best interest of their child.

Since their child is unable to participate directly in the decision-making process, parents must grant informed permission for the agreed upon treatment.

7.1.c. Role of the Provider: healthcare providers are obligated to respect, support, and empower

parents to participate actively in decision making for their child. Healthcare providers should

- work with parents to assess and determine the nature of the child's health problems;
- provide parents with comprehensive information about treatment options, including nontreatment;
- obtain informed parental permission; and
- once a treatment option has been selected, to evaluate treatment with the parents on an ongoing basis to determine if the treatment plan needs to be reconsidered.

If providers believe that parental refusal of permission for a specific treatment will result in predictable harm to the health or well-being of the child, they are obligated to participate in conflict resolution procedures. If the disagreement cannot be resolved, the healthcare providers have a duty to seek permission for treatment as provided by law.

7.1.d. Role of the Institution: the institution is obligated to educate and inform parents and providers of their rights and responsibilities in the decision-making process. It should

- create an environment that respects the child as a person;
- encourage parents and providers to work together in making decisions;
- establish necessary policies and procedures to support shared decision making and educate providers about these policies;
- provide mechanisms for conflict resolution when providers and parents disagree.

**7.2. Minors with a developing capacity for participation in treatment decision** (usually refers to elementary school-aged children):

7.2.a. Role of the Minor: children with a developing capacity for autonomy and self-determination should participate in treatment decision making to the fullest extent of their capacity and

willingness to do so. The assent of the child should be solicited prior to any healthcare intervention. When children dissent, they should have access to conflict resolution procedures.

7.2.b. Role of the Parent: parents are primarily responsible for the health and well-being of their child. In making decisions involving children with developing decisional capacity, parents should

- respect and support the active involvement of the child in the decision-making process;
- obtain and provide necessary information;
- work with their child and healthcare providers to determine which treatment options pose the least risks, Harms, and burdens to their child and which options provide the greatest possibility of benefit, and attempt to balance the risks and benefits of various options;
- promote the best interests of their child;
- participate in conflict resolution when there is disagreement about what treatment is in the best interest of their child.

Whenever treatment is going to be imposed on a child who has not assented, parents should, to the best of their ability, provide their child with an explanation of why treatment is believed to be necessary in language the child can understand.

7.2.c. Role of the Provider: healthcare providers are obligated to respect, support, and empower children and their parents to participate actively in the decision-making process. In addition, healthcare providers should

- work with the child and the child's parents to assess and determine the nature of the child's health problems;
- provide parents with comprehensive information about treatment options, including nontreatment;
- obtain informed parental permission; and
- solicit the assent of the child.

The assent process includes

a. assisting the minor to the fullest extent of his or her ability to understand the nature of the child's condition;

b. disclosing to the minor the nature of the proposed treatment and what the child is likely to experience in undergoing it;

c. making a clinical assessment of the child's understanding of the situation and of the factors or people that may be influencing how the child is responding; and

d. soliciting the minor's free and uncoerced willingness to undergo the treatment.

- Whenever treatment is going to be imposed on a child who has not assented, healthcare care providers should explain in language the child can understand why treatment is believed to be necessary.
- Once a treatment option has been selected, the providers should evaluate the decision with the child and the parents on an ongoing basis to determine if the treatment plan needs to be reconsidered.
- If providers believe that parental refusal of permission for a specific treatment or respecting the dissent of the child will result in predictable harm to the health or well-being of the child, providers should participate in conflict resolution procedures. If the disagreement cannot be resolved, the healthcare providers have a duty to seek permission for treatment as provided by law.

7.2.d. Role of the organization: the organization is obligated to educate and inform children, their parents and providers of their rights and responsibilities in the decision-making process. It should also

- create an environment which respects the child as a person;

- encourage children, parents, and providers to work together in making treatment decisions;
- establish necessary policies and procedures to support shared decision making and to educate providers about these policies;
- provide mechanisms for conflict resolution when children, parents, and providers disagree.

### 7.3. Minors with Decisional Capacity

7.3.a. Role of the Minor: minors with decisional capacity should be allowed to make treatment decisions including refusal of treatment, authorization of do not resuscitate orders and decisions to withhold/withdraw life support. They should be respected as persons primarily responsible for their own health and well-being. The minor with decisional capacity should

- work with healthcare providers and consult with his/her parents, as appropriate, to determine the course of treatment;
- be regarded as having the right to refuse treatment, including life-sustaining treatment;
- be encouraged to participate in conflict resolution, when there is disagreement regarding appropriate treatment.

7.3.b. Role of the Parent: parents of minors with decisional capacity should:

- act as "consultants" and assist the minor to make appropriate decisions by providing information and support;
- be encouraged to participate in conflict resolution when there is disagreement regarding appropriate treatment.

7.3.c. Role of the Provider: healthcare providers are obligated to assist the minor with decisional capacity to make informed treatment decisions and to respect these decisions. Further, healthcare providers should

- work with the minor to assess and determine the nature of the health problems;
- provide the minor with comprehensive information about treatment options, including nontreatment;
- obtain informed consent;
- advocate on behalf of the minor's autonomy and assist the minor to define and negotiate an appropriate relationship to his/her parents regarding treatment decision making.
- Once a treatment option has been selected, to evaluate the decision with the minor on an ongoing basis to determine if the treatment plan needs to be reconsidered.

7.3.d. Role of the institution: the institution is obligated to inform minors with decisional capacity about their right to make treatment decisions. Institutions should

- create an environment that respects the rights of minors;
- encourage minors, parents, and providers to work together in making treatment decisions;
- establish necessary policies and procedures to support shared decision making and to educate providers about these policies;
- provide mechanisms for conflict resolution when minors, parents, and providers disagree.

**7.4. Decisional Capacity:** The assessment of whether or not a minor has decisional capacity is the shared responsibility of the minor, the parents, and the providers. Decisional capacity can be thought of as the ability to participate in an informed consent process.

7.4.a. Decisional capacity must be assessed in relationship to each particular treatment decision. The desires of the minor regarding specific treatment alternatives should not be used as evidence

of his or her decisional capacity. Parents and providers should

- explain to the minor the meaning and significance of the assessment of decisional capacity,
- explain how the decision about capacity will be made,
- and support the minor to participate in the process to his or her fullest ability.

7.4.b. At a minimum, it should be determined that the minor has a reasonable understanding, that is, a level of understanding that meets his or her needs in the decision-making process, regarding

- the nature of his or her health problem;
- treatment options and their potential benefits and burdens;
- the consequences of treatment options, including nontreatment.

The minor must also be able to

- think about options and reach a conclusion that reflects his or her values;
- communicate the decision to care givers (verbally or nonverbally).

7.4.c. Determinations of capacity and its justification should be noted in the minor's medical record.

7.4.d. Providers should be aware that cultural influences may impact the way in which a minor demonstrates capacity.

7.4.e. Treatments involving significant risks to the health or well-being of the minor require a greater certainty about the capacity of the minor than routine treatment. Honoring the minor's refusal of a treatment believed to be of clear benefit will also require greater confidence about the minor's decisional capacity on the part of providers and parents.

7.4.f. In some cases lack of capacity may have a reversible cause, such as medication, or acute

pain. The provider should attempt to restore the patient's capacity prior to decision making if possible. In some situations, treatment decisions might be postponed until the patient has recovered capacity.

7.4.g. If the minor believes that he or she has decisional capacity and either the parents or the providers disagree, the situation may require conflict resolution.

**7.5. Surrogate Decision Makers for Minors with Decisional Capacity:** Although parents are commonly viewed as appropriate surrogates for minors who have lost the ability to participate in decision making, minors with decisional capacity should be allowed to name any person with decisional capacity to act on their behalf in the event they lose capacity.

7.5.a. Emancipated minors in some jurisdictions may be able to complete legally valid documents designating a durable power of attorney for healthcare decision making. Minors with decisional capacity should be given this same option. The minor should be told if such a document is not legally valid; however, the minor should be assured that the person named will be allowed to participate in healthcare treatment decisions. Such statements should be made part of the minor's permanent medical record.

7.5.b. In the event that a minor with decisional capacity has not designated a surrogate, it should be assumed that the minor's parents or guardian is the appropriate surrogate. The rights of parents or guardians to act as surrogate decision makers for minors may be limited.

7.5.c. Conflicts between parents or guardians and a patient-designated surrogate regarding appropriate care of a minor who has lost decisional capacity may warrant conflict resolution.

7.5.d. If healthcare providers doubt that a parent, guardian, or any other surrogate has decision-making capacity or is acting in the best interest of the minor, providers should seek conflict resolution. Legal resolution should only be considered as a last resort.

## 7.6. Patient Self-Determination Act and Advance Directives

7.6.a. Legally emancipated minors should be treated the same as any adult with regard to the requirements of the Patient Self-Determination Act. They should be informed about their rights to choose and refuse healthcare interventions and about their right to make advance directives and a durable power of attorney for healthcare decision. Advance directives made by legally emancipated minors must be made part of the minor's permanent medical record and should be honored.

7.6.b. Minors with decisional capacity should be allowed to make advance directives and to name the person they want to be their surrogate decision maker. If such a document is not legally binding, the minor should be told and assured that it will help to guide decision making. The minor should also be assured that the person he or she has named as a surrogate will be allowed to participate in decision making. Advance directives made by a minor with decisional capacity should be made part of the minor's permanent medical record and should be honored.

7.6.c. Minors with a developing capacity who may be at risk of losing their ability to participate in treatment decision making should be encouraged to express their treatment preferences so that their preferences may be reflected in healthcare decisions made in the event of their loss of the ability to participate in decision making. These preferences should be documented and incorporated into the minor's medical record.

**7.7. Confidentiality, Recordkeeping, and Access to Records:** Since parents may have a limited legal right of access to the medical records of their children, any promise of confidentiality made to a minor creates special challenges for healthcare providers and healthcare providing organizations. The task force has been unable to resolve these issues fully. However, we offer the following guidance:

7.7.a. Although confidentiality is an essential aspect of the patient-provider relationship, pro-

viders should inform minors of limitations on their ability to protect confidentiality. Providers are also obligated to notify minors when a promise of confidentiality cannot be made or honored.

7.7.b. Since parents need access to records regarding financial aspects of the care of minors, special mechanisms are required to allow this access in a manner that protects confidentiality.

7.7.c. Providers must exercise precautions regarding what information is placed in the minor's medical records so that confidences promised to the minor are not betrayed.

7.7.d. Full implementation of the recommendations of this task force regarding minors with decisional capacity may require changes in laws regarding parental access to records and parental notification regarding treatment.

## 8. Conclusion

When this project began, the initial question was, *How does the Patient Self-Determination Act relate to minors?* However, as soon as we began to discuss that question, it became clear that how information is provided to minors and to their families, and how decisions are made in relation to the care of minors presents multiple, general questions that need to be considered. These questions and our recommendations took us much beyond the Patient Self-Determination Act.

Our group of fifteen to twenty diverse care providers and parents met faithfully to struggle our way through writing this document. We encouraged open, honest sharing of opinions while maintaining respect and consideration for the time and energy each member was spending on the project. At times, we got too specific, or went off on a tangent that turned out to be a "red herring." Frequently, we became distracted about what was legal, or by an accepted community practice, until someone would remind us that our agenda was to try to elucidate how things ought to be in an ethical, caring, healthcare environment for minors. We concluded repeatedly that we should be as clear and consistent as possible with our primary agenda, recognizing that we might have to educate, discuss, and potentially help bring the "real world" closer to the world we could visualize.

We do clearly recognize that each and every institution, organization, provider, and community will have to struggle with some of these issues on their own, and that this document will not (and should not) be accepted as is, nor incorporated intact into any institution's policy. However, our hope is to help identify the issues and provide some thoughtful guidance to those who work with minors. If through this process we can initiate, encourage, or support conversations and thinking about these issues, we will have succeeded.

## In Loving Memory

The Center for Practical Bioethics and the Task Force on the Healthcare Rights of Minors dedicate this work to the memory of William G. Bartholome, MD, MTS, in recognition of his leadership and exemplary commitment to the ethical rights of children. Dr. Bartholome died in August 1999, a few months after reviewing this document a final time.

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