



SOCIETY OF  
PEDIATRIC NURSES

## SPN Informational Paper: Pediatric Bill of Rights

### INTRODUCTION

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The Society of Pediatric Nurses (SPN) recognizes that pediatric health care should be child- and family-centered and delivered in a way that is acceptable to patients, families, and healthcare providers (Society of Pediatric Nurses, 2008). The expectation is that pediatric nurses, patients, families/legal guardians, and other healthcare providers will gain knowledge from this Informational Paper and consider incorporating its premises in all healthcare settings across the continuum of care, thereby enhancing the child- and family-centered environment of care. Utilizing this information on pediatric rights demonstrates advocacy, which is an important component of standards of practice.

### RATIONALE AND SUPPORTING INFORMATION

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Healthcare providers strive to provide the highest quality of care and safety based upon best evidence, clinician expertise, and patient values or preferences. Effective pediatric health care requires collaboration between patients, families/legal guardians, pediatric nurses, and other healthcare professionals. Open communication, respect for personal values, and sensitivity to cultural beliefs and lifestyles are integral components in the provision of optimal family-centered care. When faced with hospitalization, children and their families/legal guardians may have a ~~preconceived set of~~ expectations regarding proposed care, or they may experience a sense of uncertainty about what lies ahead. Therefore, it is important for nurses to assess the individual patient and family's biopsychosocial needs and expectations so that they can help them have a clear understanding of what to expect in the healthcare setting and to outline their rights and responsibilities in the delivery of care using simple, concrete terms.

Originally developed in 1991, by the Association for the Care of Children's Health (ACCH), the Pediatric Bill of Rights has been adapted and used in many formats in healthcare organizations across the United States. The Pediatric Bill of Rights is a statement of the rights to which children and their families are entitled as recipients of care as in healthcare settings. These rights align with ethical principles including autonomy, beneficence, and non-maleficence. These rights can be exercised by the patient or on the patient's behalf by a parent or legal caregiver. It communicates the positive rights that healthcare providers and organizations should provide patients and families, thereby providing information, offering a partnership with the healthcare team, and granting autonomy over health care decisions (Child Life Council, Inc., 2002).

### RECOMMENDED GUIDANCE

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The following premises are outlined in the Pediatric Bill of Rights: respect, privacy, information, support, family-centered care, choices, and flexibility. SPN believes that healthcare agencies should provide a bill of rights for children and their families in all healthcare settings. Pediatric nurses should inform children and families/legal guardians of their rights as patients while advocating for them to be active members of the healthcare team, partner with healthcare providers, and participate in the plan of care. SPN recommends that pediatric nurses utilize resources that support this bill of rights such as the Choosing Wisely initiative (AAN, 2015).

## ATTACHMENT(S)

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Attachment A – Pediatric Bill of Rights

### REFERENCES

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American Academy of Nursing. (2015). Choosing wisely. Retrieved from <http://www.aannet.org/initiatives/choosing-wisely>

Child Life Council, Inc. (2002). A Pediatric Bill of Rights. Rockville, MD: Child Life Council, Inc.

Society of Pediatric Nurses. (2008). Position Statement on Family-Centered Care Content in the Nursing Education Curriculum. Retrieved from <http://www.pedsnurses.org/p/cm/ld/fid=57&tid=28&sid=55>

Society of Pediatric Nurses. (2014). SPN Vision Statement. Retrieved from <http://www.pedsnurses.org/p/cm/ld/fid=8>

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### REVIEWED AND APPROVED BY:

SPN Child Advocacy Committee:  
Date: 12/10/2013

Subject Matter Expert/Task Force: Kathy Van Allen, MSN, RN, CPN  
Date: 10/08/2016  
Sally Fowler  
Date: 12/26/2018

SPN Board of Directors:  
Date: 10/14/2016  
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## **Attachment A - Pediatric Bill of Rights**

### **Bill of Rights for Children and Teens**

In this healthcare setting, you and your family/legal guardian have the right to:

#### **Respect**

- Have people tell you their names, what is going on, and why.
- Feel lots of different feelings, and for people to understand that sometimes you may need to cry if you feel afraid or hurt.

#### **Privacy**

- Have people honor your privacy, as long as it is safe for you.
- Have your information shared only with people who need to know so they can assist in your care.

#### **Information**

- Get information about your care in a language you can understand.
- Ask questions.
- Tell us about yourself, what you need, and how you feel.

#### **Support**

- Talk or play with people who know how to help when you have questions or problems.
- Spend as little time waiting and go home as quickly as possible.
- Be as comfortable and have as little pain as possible.

#### **Family-centered Care**

- Have your healthcare team meet with you and your family to plan what is best for you.
- Have access to things that help you feel safe and comfortable, like your favorite toy from home or your own clothing when it is okay.
- Have your family help take care of you, stay near you, and be with you when things about your care are explained to you.

#### **Choices**

- Choose what you want when possible and have us support your choices.

#### **Flexibility**

- Have all of your interests and needs, not just those related to illness or disability, considered.
- For time to rest, to play and to learn in ways that help you feel your best.

### **Bill of Rights for Family Members or Legal Guardians**

In this healthcare setting, you and your child have the right to:

#### **Respect**

- Patient confidentiality, privacy and diversity.
- Ask your providers to introduce themselves and explain their role in your child's care.

- To expect, your providers to stop, listen and acknowledge your needs and your expertise in what is best for your family.

### **Privacy**

- Expect the things you tell your providers in confidence will be kept private as long as it is consistent with the law and safe for you and your child. Your providers promise to report any patient safety issues and take prompt action.

### **Information**

- Have the services/treatments explained to you in detail by someone who speaks your language, including a certified medical interpreter if needed, and we will welcome your questions. You can ask to have someone from your family or another support person with you when receiving explanations.
- Know about your child's condition and treatment plan.
- Ask to review your child's medical record with healthcare personnel.
- Detailed information about your child's medical bill.
- Know the process for taking care of your concerns or complaints.

### **Support**

- Stay with your child during most medical treatments, if you choose.
- A place for at least one family member to stay near your child if they are hospitalized.
- Talk with health professionals about your feelings, questions, problems, or concerns. They will listen to you and respect your feelings.
- Help with connecting to other families who have had experiences like yours.

### **Family-Centered Care**

- Know who the many people are that take care of your child in the healthcare setting, and what they do.
- Expect to have your child cared for by doctors, nurses, and others who know how to care for children and youth.
- Expect all healthcare providers to make patient safety and quality care their priority.
- Participate in the planning and care of your child at whatever level is most comfortable to you since you know your child best and to know your ideas and concerns are welcome.
- Be taught before you leave the healthcare setting all the information you will need to take care of your child at home, and to be provided with follow-up appointment dates/times and who to call in case of an emergency.
- Transfer your child to another healthcare setting, when necessary, with every effort made to not move your child until you have been told why.
- Receive a list of possible primary care physicians, if you currently do not have one, a health care provider help you make a choice before discharge from the hospital setting.
- Be given information about people and places in your community that can help you.

### **Choices**

- Work in partnership with your healthcare provider to make decisions about your child's treatment options and care.
- Refuse treatments as permitted by law.
- Change your mind about care for your child even if you have already given permission.
- Ask for a second opinion from another doctor. You can ask for a specialist to see your child.

**Flexibility**

- Expect your healthcare provider to consider all your child's interests and needs, not just those related to illness or disability.
- Know your child will be cared for by people who understand the needs and concerns of children and teenagers.
- Expect your healthcare provider to try to keep your child's schedule and activities as normal as possible.

**Family Responsibilities**

In this healthcare setting, you have the responsibility to:

- Ask questions if you don't understand what we are telling or showing you.
- Help develop a plan for controlling your child's pain and providing comfort.
- Show respect for the knowledge and skills of the healthcare professionals you encounter.
- Tell us your concerns in a clear and kind way.
- Participate in the planning and care of your child at your level of comfort.
- Show respect for the rights of other children and families in the healthcare setting.

This Pediatric Bill of Rights was written in 2013 by SPN Child Advocacy Committee Members:

Niki Fogg, MS, RN, CPN

Lori Lauver, PhD, RN, CPN, CNE

Valerie Badgett, MS, RN

In collaboration with Child Life Council Members:

Erin Panzella, BS, CCLS

Christine Elder, CCLS