

# SPN DEPARTMENT

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## The Pediatric Bill of Rights<sup>1,2,3,4</sup>



The pediatric nurse's role as an advocate includes safeguarding the interests of children and their families, informing them of their rights and responsibilities, and assisting them in making informed decisions (Kyle & Carman, 2013). To this end, the Society of Pediatric Nurses (SPN) encourages nurses to incorporate and support the utilization of a pediatric-specific bill of rights in the care of children in all healthcare settings. The Pediatric Bill of Rights (second edition, 1996) is a statement of rights to which pediatric patients and their families are entitled as healthcare recipients. The Association for the Care of Children's Health (ACCH) developed the first Pediatric Bill of Rights (1991) to affirm their mission to ensure family-centered, psychosocially comprehensive, and developmentally appropriate care to children and their families. The ACCH's goal was to inform healthcare providers, parents, and children that recipients of care had basic rights and providers of care had the responsibility to observe and provide for those rights.

Since the Bill of Rights was inaugurated, the document has been adapted and adopted nationally by free-standing children's hospitals and pediatric units within general hospitals (Kyle & Carman, 2013). Many institutions have modified the document to reflect environmental and cultural nuances of their institution. This practice concurs with ACCH's vision that healthcare systems and practices are most effective when planned, coordinated, delivered, and

evaluated through collaboration between families, patients, and providers. An example of incorporating regional specifics and directing statewide support is New York, which finalized the adoption of new standards and enforced regulations requiring all hospitals within the state to post and provide a bill of rights for patients notifying patients and families of the protections provided by the regulations related to the care of children (Business Wire, Inc., 2014).

In 2013 the SPN Board tasked the organization's Child Advocacy Committee to review for relevance and applicability to the current healthcare climate the SPN's Position Statement on this document. A collaborative task force composed of committee members was formed to review and revise the document. During the process there were numerous consultations with child life specialists to ensure realistic developmentally appropriate expectations. In addition, language was revised to be more developmentally appropriate and to reflect early 21st century trends in healthcare. As the majority of children receiving healthcare are not hospitalized and the highest proportion of pediatric healthcare delivery is outside the hospital setting, a major update to the document was to change "hospital" to "all settings in which the care of children occurs" (Centers for Disease Control and Prevention, 2012).

SPN encourages its members to actively advocate for the rights of children and teens and also their parents to receive respect, information, support, privacy, choice, flexibility, and family-centered care whenever and wherever they interact with healthcare providers.

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### Position Statement on the Pediatric Bill of Rights

#### Purpose

The Society of Pediatric Nurses (SPN) recognizes that pediatric healthcare should be family-centered and delivered under conditions that are acceptable to patients,

families, and healthcare providers (SPN, 2008). The expectation is that pediatric nurses, patients, families/legal guardians, and other healthcare providers will support this position statement on the Pediatric Bill of Rights by incorporating its premises in all healthcare settings and thereby enhancing the child- and family-centered environment of care.

## Rationale

SPN strives “to be the premier resource for nurses caring for children and their families” (SPN, 2014). Healthcare providers strive to provide the highest quality of care and safety based on evidence from clinical and health services research. 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 medical 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 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.

## Background

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 medical care as in healthcare settings. 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 medical decisions (Child Life Council, Inc., 2002).

## Position

It is the position of SPN 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.

## 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 and what you need and 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
- 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 to 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

- We will consider your interests and needs, not just those related to illness or disability
- 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

- We promise to respect patient confidentiality, privacy, and diversity.
- We will introduce ourselves. We will explain our role in your child’s care.

- We recognize you are the experts in your child's care. We promise to stop, listen, and acknowledge your needs and what is best for your family.

#### Privacy

- We will keep the things you tell us in confidence private as long as it is consistent with the law and safe for you and your child. We 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 we are explaining things to you.
- Know about your child's condition and treatment plan. You have the right to 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

- If you choose, you can stay with your child during most medical treatments.
- If your child is hospitalized, we will provide a place for at least one family member to stay near your child.
- You can talk with health professionals about your feelings, questions, problems, or concerns. They will listen to you and respect your feelings.
- We can help you connect with other families who have had experiences like yours.

#### Family-centered care

- There are many people who take care of your child in the healthcare setting. You have the right to know who they are and what they do.
- You can expect to have your child cared for by doctors, nurses, and others who know how to care for children and youth.
- You can expect all healthcare providers to make patient safety and quality care their priority.
- We respect that you know your child best and welcome your ideas and concerns. We will encourage you to participate in the planning and care of your child at whatever level is most comfortable to you.
- Teaching will be provided to you before you leave the healthcare setting, which will include all the information you will need to take care of your child at home. We will also provide you with follow-up appointment dates/times and whom to call in case of an emergency.
- If it is necessary to transfer your child to another healthcare setting, we will make every effort not to move your child until you have been told why.
- If you do not have a primary care physician, a healthcare provider will provide you with a list and help you make a choice before discharge from the

hospital setting.

- We will tell you about people and places in your community that can help you.

#### Choices

- We will work in partnership with you to make decisions about your child's treatment options and care.
- You may refuse treatments as permitted by law.
- You can change your mind about care for your child even if you have already given permission.
- You can ask for a second opinion from another doctor. You can ask for a specialist to see your child.

#### Flexibility

- We will consider all of your child's interests and needs, not just those related to illness or disability.
- Your child will be cared for by people who understand the needs and concerns of children and teenagers.
- We will 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
- Respect the knowledge and skills of the healthcare professionals
- Tell us your concerns in a clear and kind way
- Participate in the planning and care of your child at your level of comfort
- Respect the rights of other children and families in the healthcare setting

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